High Treatment Drop-out Rate of Children with Pervasive Developmental Disorders

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Abstract

Objective: The objective of this study was to evaluate the course and outcome of children with pervasive developmental disorders presenting to hospital clinics in India.
Patients and Methods: Forty two children with pervasive developmental disorders were identified from 2671 case records of children attending the Child and Adolescent Psychiatric Clinic during a 10-year period. Elaborate attempts were made to trace the patients and determine their current status.
Results: The follow-up rate was very low, and only 10 of the 42 children were eventually contacted. The attempt at evaluating the outcomes had to be abandoned.
Conclusions: The reasons for the high attrition rate in children with pervasive developmental disorders found in this study were not totally clear, although a combination of psychosocial and clinical factors seems likely. A lack of facilities, particularly for specialised long-term treatment, could also have contributed to the high drop-out rate.

Key words: *Patient dropout, Pervasive developmental disorders*

Introduction

Patients dropping out of treatment is a common problem in psychiatric settings across all ages, diagnoses, and socio-cultural set-ups. Several authoritative reviews in the field of mental health have suggested that 20% to 57% of general psychiatric clinic patients are not available for evaluation after they have been assessed once.[1] Studies have also shown that a similar proportion of children, from 28% to 68%, also drop out of treatment.[2-5] However, such studies are fewer in number. Studies from non-western settings are especially rare.

Several factors that could account for the high default rate in children have been examined in different studies. These have included socio-demographic variables, clinical characteristics, parental psychopathology and attitudes, assessment procedures, and sources of stress. However, there is no clear consensus regarding these factors, partly because of several methodological problems such as the definition of 'drop out', or the stage at which dropouts have been studied.[6] A similar confusion exists about the contribution of presenting problems or diagnoses to the process of dropping out. Failure to attend clinics has been found to be associated with problems of non-attendance elsewhere, for example, running away or truanting,[7] whereas anxious children have been found to be more likely to attend regularly.[3] Some authors have reported that children with infantile autism or hyperkinetic disorder are less likely to drop out.[6] Others have found that children with diagnoses of psychosis, epilepsy, or organic brain syndromes are more likely to discontinue treatment.[8]

In recent decades, knowledge about children with pervasive developmental disorders (PDD) has increased tremendously with the accumulation of research evidence supporting a biological basis, and offering clues to more effective ways of treatment.[9] However, despite the increasing research interest in PDD worldwide, data from developing settings such as India are scarce. Although such children are seen and treated in several centres around the country, information about how they and their families fare is scant. Such information is necessary because socio-cultural factors might influence presentation, treatment, and outcome of PDD, as they do in other psychiatric disorders such as schizophrenia.

This study was therefore initially planned as a long-term follow-up of a cohort of children with PDD presenting to

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the Child and Adolescent Psychiatric Clinic CAPC of a teaching hospital in the North Indian town of Chandigarh. The objectives were to evaluate the course and outcomes of these children and to assess the problems being faced by their caregivers. However, as subsequently described, these objectives could not be met because of the small number of children who were eventually traced and evaluated. The following is therefore a description of the methods used to trace these children and the possible reasons for such a high drop-out rate.

Patients and Methods

Identification of the Study Group

The study group was selected from children presenting to the CAPC at the Department of Psychiatry, Postgraduate Institute of Medical Education and Research in Chandigarh, India. The CAPC is a weekly outpatient clinic that is run for children and adolescents who have psychiatric problems. Inpatient facilities are also available for those children and adolescents who require them. Children who have PDD are referred from a variety of sources. Many of them are brought by their parents, relatives, or friends. Others are referred to the CAPC by schools, general practitioners, or other hospital departments.

All children attending the clinic are examined in detail by a multidisciplinary team headed by the consultant psychiatrist, and including other psychiatrists, psychologists, social workers, play therapists, and vocational guidance instructors. Following this assessment, a multiaxial diagnosis is usually made, and individual treatment plans formulated. Intervention consists of pharmacotherapy (rarely used), brief behavioural and educational interventions with the child, and most importantly, counselling, support, and education of parents about the disorder. To ensure continuity of care, interventions are normally carried out by the same team members who initially assessed the child. Follow-up is mainly in the form of outpatient visits; the frequency of visits and the duration of sessions vary depending on the type of intervention. Home or school visits are also undertaken on occasions. Some children with severe forms of disturbance are occasionally admitted to the hospital. Parents are also informed about other educational and rehabilitative facilities that are available, and encouraged to make contact with them. The families are also referred to these centres if they so wish. However, the number of such services is limited and most families are unable to access these.

All assessments are carried out using a comprehensive semi-structured proforma. The case notes thus contain detailed information on socio-demographic parameters, history of illness, results of physical and mental state examination, psychometric tests (IQ), results of playroom observation, final (multiaxial) diagnosis, and notes about follow-up visits.

The case records of all children (n = 2671) who had been assessed at the clinic from 1989 to 1998 were screened. Forty two children with PDD, diagnosed according to the *International Classification of Mental and Behavioural Disorders* (ICD-9[10] or ICD-10[11]) criteria, were identified. All patients with ICD-9 diagnoses were re-diagnosed according to the ICD-10 and fulfilled the criteria for PDD.

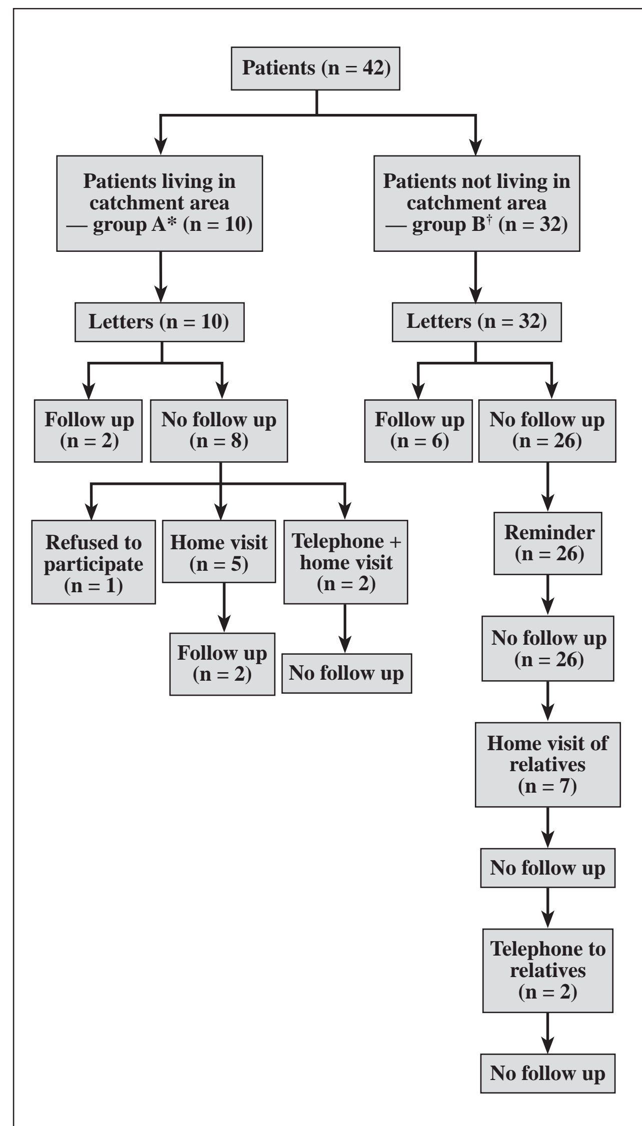
Follow-up Procedure

The procedure for tracing patients is shown in Figure 1. The addresses of all 42 patients were noted and were divided into 2 groups as follows:

- group A (n = 10) consisted of patients from the catchment area, i.e., people living in and around Chandigarh (a radius of <30 km)
- group B (n = 32) consisted of people living outside the catchment area (>30 km).

A 4-stage process was followed to trace these patients. At stage I, all the patients in both groups were sent letters for a follow-up visit. At stage II, a telephone call was made to 2 patients and a home visit was done for 5 patients in

Figure 1. Procedure for tracing patients.



* ***Four patients from group A were followed up.***
† ***Six patients from group B were followed up.***

group A. A reminder was sent to 26 patients in group B. At stage III, a home visit was done for the 2 patients in group A who could not be contacted by telephone, as well as home visits to the relatives of the 7 patients in group B who were living in the catchment area, requesting that the patients make contact whenever they were in town. At stage IV, a telephone call was made to 2 relatives of patients in group B.

Four patients in group A had come for a follow-up visit. Two families came after being sent letters (stage I), and 2 following a home visit (stages II and III). One patient in this group had died in an accident, 1 patient's family refused to participate when approached, 3 patients had moved away, and 1 patient's family could not be contacted despite telephone calls and a home visit. In group B, 6 of the 32 patients were eventually followed-up. All 6 patients responded after being sent letters (stage I). Stages II to IV did not yield any further follow-up visits.

For assessment purposes the participants were divided into 2 groups:

- group 1 was the non-follow-up group and included patients who did not have follow-up despite elaborate efforts to persuade them to do so — there were 32 such children, including 6 from the catchment area and 26 from the non-catchment area.
- group 2 was the follow-up group and included 10 patients who attended the clinic after being contacted — 4 patients were from the catchment area and 6 were from the non-catchment group.

Follow-up for the purposes of this study essentially referred to long-term follow-up for several years. Patients and their families who attended after being contacted constituted the follow-up group. Patients and their families who did not attend, even after being contacted, were the 'non-follow-up' cases. Some families could not be contacted, or did not attend because of other reasons.

Assessments were made for the follow-up group. For the clinical assessment, the patients and their families were interviewed in detail by a consultant psychiatrist and a clinical psychologist regarding their course of illness, present status of illness, and treatment. Wherever possible, carers were again educated about the condition and the need for treatment emphasised. Simple behavioural measures were suggested and drug treatment, if indicated, was instituted. For assessment of stress/burden and coping among parents or relatives, family members were assessed for the degree of burden, stress experienced, and coping strategies adopted. The following tools were used.

The Family Assessment Schedule was used to measure stress and coping among the parents and families.[12] This instrument was originally designed for use for children with learning disability. The schedule has 2 major sections:

- section I comprises perceived stress in the family and is subdivided into 4 areas, namely daily care stress, family emotional stress, social stress, and financial stress, with a total of 11 subscales with a 5-point rating
- section II has 5 areas of awareness about the child's problem, expectations and attitudes, child rearing practices, social support, and global family adaptation. There are a total of 9 sub-scales and scoring is on a 4-point scale.

Pai and Kapur's Interview Schedule was used for measuring the burden to the family.[13] This scale assesses both objective and subjective burden. Objective burden is assessed by 24 items grouped in 6 areas, namely financial burden, disruption of family interaction, family routine and family leisure, and effect on the physical and mental health of the carers. Subjective burden is assessed by a single question. Each item is rated on a 3-point scale. A global rating of the family burden is also made on the same 3-point scale.

The data for the non-follow-up group was retrieved from the files/case notes. These were used to make an assessment of the course of illness, treatment sought, and status at last follow-up. Burden and stress among carers could not be determined for this group.

Results

Demographic Profile

Table 1 shows the socio-demographic profile of the patients of the 2 groups. The non-follow-up group had significantly

Table 1. Sociodemographic profile of children with pervasive developmental disorders.

Variables	Group 1* (n = 32)	Group 2* (n = 10)	t/χ^2
Mean age (standard deviation) [months]	61.87 (32.67)	61.70 (35.41)	NS
Gender (%)			
Male	24 (75)	8 (80)	NS
Female	8 (25)	2 (20)	
Education† (%)			
Illiterate	25 (78)	9 (90)	NS
Literate	7 (22)	1 (10)	
Socio-economic status (%)			
Upper class	12 (38)	2 (20)	3.37‡
Middle class	11 (35)	2 (20)	
Lower class	9 (27)	6 (60)	
Locality (%)			
Rural	9 (27)	5 (50)	NS
Urban	23 (73)	5 (50)	
Distance from clinic (%)			
Up to 30 km	13 (41)	4 (40)	NS
More than 30 km	19 (59)	6 (60)	
Religion (%)			
Hindu	21 (66)	8 (80)	NS
Others	11 (34)	2 (20)	
Source of referral (%)			
Self/relatives	20 (62)	2 (20)	5.52‡
Friends	12 (38)	8 (80)	

* *Group 1 = non-follow-up group; group 2 = follow-up group.*
† *Refers to whether patients had been able to complete some years of schooling.*
‡ *$p < 0.01$.*
Abbreviation: *NS = not significant.*

more children from upper and middle class families, as well as more self-referrals. There were no significant differences in any of the other variables.

Clinical Profile

Table 2 shows a comparison between the 2 groups of children with PDD for certain clinical variables. The majority of the children (45%) had a diagnosis of childhood autism, followed by childhood disintegrative disorder (29%), and other types of PDD (26%). There were no significant differences in age at intake/onset, duration of illness, IQ scores, and treatment. Understandably, the number of follow-ups were significantly greater in the follow-up group. Although the outcome in the non-follow-up group was determined retrospectively, the outcome did not differ significantly between the 2 groups.

Comparison of the Study Groups with Other Children at the Clinic

Table 3 shows a comparison of some variables between all patients attending the CAPC and children with PDD during the period 1989 to 1998. Children with PDD were significantly younger, more likely to be boys, and more likely to be residing outside the catchment area. There were no differences in family income between the 2 groups. The follow-up rate of children with PDD was significantly poorer than the other children. Sixty seven percent of the children with PDD had dropped out after the initial visit compared with 40% of the general patients at the CAPC.

Table 2. Clinical profile of children with pervasive developmental disorders.

Variables	Group 1* (n = 32)	Group 2* (n = 10)	t/χ^2
Diagnosis (%)			
TA	15 (48)	4 (40)	NS
CDD	8 (25)	4 (40)	
OPDD	9 (27)	2 (20)	
Age at intake (standard deviation) [months]	61.87 (32.67)	61.70 (35.41)	NS
Age of onset (standard deviation) [months]	21.37 (22.61)	24.30 (89.00)	NS
Duration of illness (standard deviation) [months]	42.31 (29.15)	35.50 (26.00)	NS
IQ (standard deviation)	52.57 (21.29)	57.8 (27.18)	NS
Treatment (%)			
Pharmacological	21 (66)	6 (60)	NS
Non-pharmacological	11 (34)	4 (40)	
Duration of follow-up (range in months)	0-52	13-126	—
Number of follow-up visits (standard deviation)	2.56 (4.46)	6.7 (11.89)	5.63†
Clinical status‡ (%)			
Same	23 (72)	5 (50)	NS
Improved	8 (25)	5 (50)	
Worsened	1 (3)	—	

* *Group 1 = non-follow-up group; group 2 = follow-up group.*
† $p < 0.01$.
‡ *For the non-follow-up group, status at last visit was considered.*
Abbreviations: *TA = typical autism; CDD = childhood disintegrative disorder; OPDD = other pervasive developmental disorders; NS = not significant.*

Burden, Stress, and Coping of Carers

Ratings of burden, stress, and coping of the family members were available only for those 10 children who could be traced. Most of the caregivers (n = 7) had felt some sort of burden at one time or another while caring for the patient. The burden was highest in the areas of disruption of family routine and family interaction. Despite this high prevalence of objectively rated burden, only 3 families reported some degree of subjective burden, reflecting a high degree of tolerance on their part. Stress was commonly reported in association with daily care of the child (n = 7), followed by emotional stress (n = 4) and social stress (n = 3). Surprisingly, very few families reported financial burden or stress. Half of the families (50%) displayed an adequate level of awareness and had received adequate information about autism and autistic-like conditions. A smaller number (40%) had lowered their expectations, adopted favourable rearing practices, and were receiving adequate social support.

Table 3. Comparisons between all patients attending the child and adolescent psychiatric clinic and children with pervasive developmental disorders.

Variables	Groups		χ^2
	All children (n = 2374)	Children with pervasive developmental disorders (n = 42)	
Age (%) [years]			
≤4	261 (11)	22 (53)	77.85*
5-9	826 (35)	17 (40)	
10-14	1287 (54)	3 (7)	
Gender (%)			
Male	1467 (62)	32 (76)	3.36†
Female	907 (38)	10 (24)	
Family income (%) [rupees]			
≤750	144 (21)	9 (21)	NS
750-1499	103 (15)	6 (14)	
1500-2499	80 (12)	8 (19)	
2500-3999	90 (13)	5 (12)	
4000-6000	94 (14)	10 (24)	
>6000	156 (23)	4 (10)	
Not known	10 (2)	0	
Distance from clinic (%)			
Catchment area (<30 km)	975 (41)	5 (12)	14.56*
Non-catchment area (>30 km)	1399 (59)	37 (88)	
No follow-ups (%)	965 (40)	28(67)	11.54*

* $p < 0.01$.
† $p < 0.05$.
Abbreviation: *NS = not significant.*

Discussion

This study represents one of the first attempts to follow up children with PDD who attend hospital clinics in India. The study was a part of a larger exercise to determine the prevalence and clinical profile of PDD and its subtypes in the same group of children. However, since only 10 children could be followed up, the intended objectives of examining the outcome of children with PDD could not be met.

Instead, the conspicuous finding of this study was the abysmally low follow-up rate over a period ranging from 13 to 126 months among children with PDD. Almost all patients and their families had stopped coming to the clinic, and only 10 (24%) agreed to do so after being contacted. It was found that half of the patients had improved and the other half had remained the same. None of these children were receiving active follow-up, and very few had sought treatment in the intervening period. A few patients and their families (n = 5) could not be traced, or were unable to attend for follow-up because of other reasons. Moreover, 67% of the patients and their families had dropped out after the first visit.

What led to this very low follow-up rate? No clear answers were forthcoming, although some speculations could be made. The drop-out rate for PDD (up to 76%) was approximately 2- to 3-fold that of other children seen at the clinic, the usual rate being around 22% to 31% for patients attending the CAPC.[8] This is within the range of 28% to 68% reported in western studies.[2-5] Studies from developing countries have also reported drop-out rates varying from approximately 22% to 27% in children presenting to CAPCs.[6] Poor awareness, the long distances that patients have to travel to reach a specialised clinic, and economic factors are cited as some of the principal psychosocial factors that account for the high number of dropouts encountered in developing countries.[6,8,14]

In this study, significant findings in this regard included the lower socio-economic status of those children with PDD who could be traced. Moreover, when compared with other children attending the clinic, children with PDD were younger, more likely to be boys, and more likely to be residing further from the hospital. Studies investigating the influence of gender on follow-up have mixed results. Some have found no association of gender with dropping out, while others have found that girls are more likely to drop out than boys.[6,15] Therefore, although psychosocial factors could have played a part they do not wholly explain the difference in drop-out rates between children with PDD and those without, since children with PDD differed minimally in these parameters from the rest of the children attending the clinic. It is uncertain whether the diagnosis of PDD made any significant contribution to the low follow-up rate, especially since the literature on this aspect is conflicting. For example, Lai et al found that children with infantile autism (and hyperkinetic disorders) were actually less likely to drop out.[6] Others such as Malhotra et al have reported that children with psychotic and organic disorders, and children who are undiagnosed, are more likely to stop attending the clinic.[8]

Patients who improve are more likely to stop coming for treatment.[14] In this respect, half of the 10 children who were eventually contacted had registered an improvement in their condition. The outcome (status at last follow-up) of the 32 children belonging to the non-follow-up group did not differ from those who could be traced. Therefore, it is highly unlikely that the remaining children could have substantially improved to the point that they did not require any help. Further, not only were the 10 children who could be traced symptomatic and their functioning impaired, their families were also severely burdened and not coping too well with the effects of the illness. This is perhaps not entirely unexpected given that other long-term follow-up studies have also reported dismal outcomes for such patients. What was surprising, however, was the reluctance of the parents or relatives to attend the clinic despite these problems.

The final speculation, therefore, has to do with the child psychiatric facilities available in developing countries in general and, particularly, the nature of treatment being offered at this centre, which is essentially a child psychiatric clinic attached to a busy teaching hospital. In India, parents of children with PDD are likely to make the first contact with any kind of medical service at such clinics or hospitals. Every attempt is made at this stage to educate, support, and counsel the parents, as well as teach them the rudiments of handling such children. At such an early stage of contact, parents are often struggling to cope with the emotional impact of the diagnosis. They seem to find the emotional aspects of the support being offered to be more useful, and seem to be (temporarily) less interested in long-term plans.[16] However, after a time they are keen to know how and where their children could receive specialised help. It is here that the system seems to fail them. The clinic, with its own problems of patient overload and lack of appropriate personnel, is mostly unable to provide anything more in terms of long-term or specialised treatment. On the other hand, facilities for special education or behaviour therapy are either almost non-existent, unaffordable, or inaccessible. Research has shown that treatment of autism requires that both the short-term and long-term needs of the child and parents be met.[17,18] The lack of facilities, which could address the long-term needs of children and their parents therefore means that parents are usually left to fend for themselves. No wonder that they choose to default follow-up after a while and either seek alternative (magico-religious) treatment or no treatment at all. This situation is quite similar to the one reported among related disorders in India such as learning disability.[18]

In conclusion, the reasons for the high attrition rate of children with PDD found in this study were not totally clear, although a combination of psychosocial and clinical factors seems likely. Lack of facilities, particularly for specialised long-term treatment, could also have contributed to the high drop-out rate. Whatever the reason, the need for such facilities to be developed, and to be accessible to and

affordable for most of those who need them, is underlined once again. Before this happens it might be too premature to discuss other aspects of PDD in a developing country such as India.

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