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Dropout from Rehabilitation and Its Associated Factors in Children with Developmental Disabilities in Tehran Rehabilitation Centers

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Abstract

Background: Improvement of the quality of life of people with developmental disorders and their full integration within society requires comprehensive mental, intellectual, and physical rehabilitation. To achieve a favorable outcome, rehabilitation should be delivered in a continuous manner and with small attrition. Research in this area is scarce.
Objectives: The current study aimed to determine the incidence of dropout from rehabilitation and its associated factors in children with developmental disorders.
Methods: In this prospective study, we recruited 225 children with developmental disorders and their parent (s) seeking rehabilitation services for the first time. They attended different centers in all regions of Tehran during 2016 - 2017. We completed a checklist using semi-structured interviews. The follow-up was performed every three months for at least six months to record the dropout from rehabilitation and the associated factors. Data analysis included the chi-square test and logistic regression.
Results: The dropout rate was found to be 10.9% within three months and reached a total of 19.3% in six months. It was significantly associated with the following factors after eliminating confounding effects: (1) poor family satisfaction with the centers in three-month analysis (OR = 10.76; CI: 2.764 - 41.906, P = 0.001) and after six months (OR = 4.51; CI: 1.30 - 15.67, P < 0.02); (2) the type of service sectors (public and charity vs. private) (OR = 7.12; CI: 2.12 - 23.93, P = 0.002); (3) moderate severity of the developmental disorder in three-month analysis (OR = 4.55; CI: 1.24 - 16.78, P < 0.03); (4) child's perceived "lack of cooperation" in attending rehabilitation sessions in six months (OR = 6.79; CI: 1.42 - 32.53, P < 0.02); and (5) the type of developmental disability (specific learning disorder vs. others) in six months (OR = 6.68; CI: 2.85 - 15.65, P < 0.001). In the open questions, the high cost of services was stated as the most important reason for dropout.
Conclusions: Our findings indicate that dropout was associated with family dissatisfaction with the low quality of services, mainly in the public and charity centers. Children with disabilities of moderate severity were most likely to drop out from rehabilitation. Specific learning disorders seem to be the most challenging type of disability that leads to the highest dropout rates. The findings provide opportunities for further research in this area and to gain more information to render rehabilitation services more efficiently.

Keywords: Adherence, Autism Spectrum Disorders, Developmental, Dropout, Intellectual Disabilities, Rehabilitation, Specific Learning Disorders

1. Background

Proper rehabilitation in children with developmental disorders is effective in improving their learning abilities (1), quality of life, and social reintegration into society. It is also a human right of these children according to international standards (2). Dropout from rehabilitation services is one of the main obstacles to a high-quality life for people with developmental disabilities and their families (1). On the other hand, the continued rehabilitation of these children and their families can prevent the emergence of additional mental health problems and comorbidities (1). Moreover, empowering these children will contribute to every nation's human capital (3).

It seems that higher levels of health literacy promote better adherence to non-pharmacological interventions in Iran (4), which means the preference of medications to non-pharmacological interventions. It seems that even in some western contexts, they have a similar issue, possi-

bly due to the additional burden that such effective treatments impose on family members (5).

Though dropout from rehabilitation has always been a major obstacle to the progress of work in this area, it has not been a major focus of research so far. Very few Iranian studies on dropout in the area of mental health have been limited to psychiatric disorders with no focus on developmental disabilities (4, 6). However, similar studies have been done in other countries on psychiatric disorders (7, 8). There are only a very small number of international studies with the main focus on autistic disorders (5, 9, 10). Ware et al. worked on dropout but in adolescents with intellectual disability (11). The situation of early termination of rehabilitation services by the users' families seems to be much worse in developing countries.

2. Objectives

The results of the present and future studies will shadow light on the main contributors to high dropout rates and would make the efforts of the care community, families, and children with disabilities more efficient.

3. Methods

3.1. Study Design

This was a prospective study using a survey method of data collection.

3.2. Ethics

Informed consent was received from the parent (s). The study was approved by the Ethics Committee of the Faculty of Medicine, Shahid Beheshti University of Medical Sciences (ethical clearance number IR.SBMU.MSB.REC.1395.216). Children were also assisted in understanding the procedure as far as possible, and they left the study whenever they wished to discontinue cooperation.

3.3. Participants

The study included all children with the defined developmental disabilities (under 18 years old) and their families who first visited the rehabilitation centers in Tehran during 2016 - 2017 until the sample size reached the number 225. Convenience sampling was performed, but in the course of selection, participants from 63 centers from all regions of Tehran were picked up in a way to have a more representative sample of the study population. Those with three groups of developmental disorders were selected, i.e., autism spectrum disorders with a global median of about 0.7% (12, 13), specific learning disorders with 10 to 20% prevalence (14), and intellectual disabilities with 1 to 3% prevalence (15). The rationale was that these developmental disabilities are more common and gain more benefit from rehabilitation (3). Concerning the sex ratio, autism spectrum disorder is commonly thought to be 2.2 to 5.8 times more common in boys than in girls (12), followed by 2 - 3 times for specific learning disorders (16) and 1.5 times for intellectual disabilities (15). Our sample included 181 boys and 44 girls. All children were checked for the inclusion criteria: the agreement of their parent (s) to participate in the study obtained through informed consent. Children were operationally defined under 18 years of age, and the diagnosis was made by a child psychiatrist categorizing them in the above-mentioned three groups. There were no exclusion criteria, but all children/families were free to leave the study at any time during the study if they wished.

Dropout operational definition was the absence from rehabilitation activities for more than a month (it did not include those who continued a home-based rehabilitation overseen by the centers or pursued the activities with other centers). All eligible individuals in contact with the centers were contacted, and they entered the study if they so wished. Visiting the centers or contacting the families continued until the sample size was completed. A total of 225 out of 389 contacts (57.84%) agreed to enter the study. Children participating in the study were attended by at least one parent, and each family was followed for at least six months. Within the first three months, 22 dropped out of rehabilitation. Within the next three months, another 17 dropped out. The overall number of dropouts reaching 39 (19.3%). At the end of the study, the remaining 163 were still continuing rehabilitation. We compared data from those in rehabilitation with the dropouts after three and six months.

3.4. Measures

The checklist included demographic and other related variables (age and sex of the child, parents' education, parents' occupation, type of developmental disorder, the severity of the developmental disorder, type of service provider center, home-to-center distance (operational definition was "time spent" to reach the center from home), family satisfaction with the services, the child's main caretaker, the existence of another sibling with or without disabilities, the presence of comorbidity in the child, the presence of illness in the parents, child's cooperation in visiting the center, rehabilitation costs, family income, and rehabilitation dropout. In selecting the variables, we considered variables used in previous literature, as well (1, 17).

Since the main aim of this research was pragmatic. i.e. to collect data to improve adherence, the parents' perceptions was the central focus of our study. Hence with the

exception of "primary clinical diagnosis" of the child, we did not use questionnaires or other objective measures for some variables such as the severity of disability or identifying coexisting physical or mental disorders and other problems in the family. An open question about other factors related to the rehabilitation dropout was included at the end of the checklist, and content analysis was performed on the answers.

3.5. Data Collection

After contacting the families and obtaining their consent, the answers to the semi-structured interview were entered into the checklist. Three months and six months later, we held the second and third interviews to check for dropouts. In case the answers were not considered reliable or the family stated they had forgotten the exact dates or details, we used medical records to improve the quality of the data. As mentioned before, the last open question also provided us with the opportunity to obtain any additional information regarding dropout from families' point of view. For this part, great care was made to give them enough convenience and time to express what they believed, to cover all other factors affecting adherence to services and dropout.

3.6. Data Analysis

All variables were originally coded and entered into the computer using SPSS V 21. Frequency, percentage, mean, and standard deviation were calculated to describe the data. A 95% confidence interval was used to express the accuracy of the estimates. The chi-square test was applied to investigate the relationship between the two classified or nominal variables, and the logistic regression test was employed to model the relationship between one dependent binary variable and one or more nominal independent variables. Then, the variables that were significant in the multiple models were entered into the final model.

4. Results

Data from a total of 225 individuals were collected in this study. Information on the age of children and parents, the sex of children, the type, and the perceived severity of their disability are presented in Tables 1 and 2.

The current comorbidities are summarized in Table 3. We did not deliberately include cleared or recovered comorbidities since our focus was on their impact on current attrition from treatment.

Eventually, out of a total of 225 participants, 39 dropped out of the rehabilitation program and 23 decided to terminate cooperation with the study. At the end of the three-month follow-up, 89.1% of the children continued rehabilitation, while 10.9% dropped out. First, statistical analysis was carried out separately for the follow-up period of three months and then six months. The model obtained for the three-month follow-up period is reflected in Table 4. Based on this model, variables including the type of service center, satisfaction with service delivery, and the severity of developmental disorder remained in the model. Based on the findings presented herein, the chance of dropout from rehabilitation after three months of follow-up was 10.76 times higher among those who were not satisfied with the services than among those who were satisfied.

At the end of the six-month follow-up, 80.7% of the children continued rehabilitation while 19.3% dropped out. The six-month follow-up model is summarized in Table 5. According to this model, the variables such as the type of developmental disorder, satisfaction rate, and the quality of "child cooperation" remained in the model. Our results revealed that the chance of dropout from rehabilitation was 6.68 times higher in children with specific learning disorders than in those with autism spectrum. Furthermore, the chance of dropout from rehabilitation was 6.79 times higher in children with poor cooperation than in those with good cooperation.

We were unable to find any significant relationship with the remaining variables such as the age and sex of the child, parent education and occupation, home-to-center distance, the existence of another sibling with or without disabilities, the presence of illness in the parents, and family income. There was also no significant correlation with the presence of somatic or psychiatric comorbidities in the child. However, those children with both somatic and psychiatric comorbidities were underrepresented among dropouts in three months: OR = 0.10 (CI: 0.01 - 0.75, P = 0.02) (Table 4); but this lost significance after six months of follow-up: OR = 0.25 (CI: 0.18 - 1.58, P = 0.53).

After examining the parents' responses to the open question, they were categorized, and the frequency and percentage were calculated at the end of the first and second three months of follow-up. The findings demonstrated that three factors, including "high rehabilitation costs", "no progress in child abilities", and "the trainer's lack of the required competencies" were markedly correlated with the rehabilitation dropout (Table 6).

5. Discussion

In the present study, after a follow-up of three months, 89.1% of the sample continued rehabilitation, and 10.9% dropped out from rehabilitation. After six months, overall, 80.7% of the subjects continued rehabilitation while the

Table 1. Age of Participants in the Study (N = 225)

Variables	Mean	Standard Deviation	Minimum	Maximum
Child's age (mon)	101.63	36.97	33	204
Mother's age (y)	37.68	5.68	24	55
Father's age (y)	42.48	6.20	30	60

Table 2. Categorical Characteristics of Participants, Their Conditions, and Type of Rehabilitation Centers in the Study (N = 225)

Variables	Frequency	Percentage
Child sex		
Girl	44	19.6
Boy	181	80.4
Type of disorder		
Specific learning disorder	47	20.9
Intellectual disabilities	14	6.2
Autism spectrum	164	72.9
Severity of disorder (family view)		
Mild	106	47.1
Moderate	89	39.6
Severe	30	13.3
Type of center		
Charity	36	16.
Private	163	72.44
Public	26	11.55

dropout reached a total of 19.3%. We did not find a correlation between the age of the child and dropout. Such a correlation has been inconsistent in other studies, as well (1). The sex of the child in our research did not have a significant effect on rehabilitation dropout either, while in some studies on general mental health, the female sex in younger children was considered one of the effective factors in dropout (1). Among the three types of developmental disorders (intellectual disabilities, autism spectrum disorders, and specific learning disorders), there was a significantly higher rate of dropout among children with specific learning disorders than in the other two groups. For this group, families emphasized that they found the competencies of trainers not meeting their expectations and claimed that their child's problem could be resolved spontaneously during school courses or via educational training by the family. In other areas of rehabilitation, the type of comorbid mental health problems has been reported to influence dropout rates (1), reaching up to 17 to 35% (17). We were not able to find similar findings after six months of follow-up.

We also checked the impact of the severity of the disabilities as perceived by the families. In the follow-up of three months, rehabilitation dropout in children with moderate perceived severity was significantly higher than mild and severe types of perceived severity. This could be a consequence of a better response to rehabilitation in the mild type while in the severe group, the smallest amount of recovery would lead to family satisfaction. In the moderate severity group, the gradient of symptom and functional recovery is not often matched with the expectation of families. In one study, a negative relationship was found between dropout from alternative services and high severity of the disability, but not mainstream treatments (5). This is in line with our findings that high severity encouraged adhering to the mainstream treatment.

In previous studies on other groups (1), the type of service centers has been effective in rehabilitation dropout. In our results of the follow-up after three months, the type of rehabilitation center was found to be significantly correlated with the frequency of rehabilitation dropout. In fact, the rehabilitation dropout in the public and charity centers was 7.12 and 4.73 times more than the dropout in private centers, respectively. Surprisingly, there was no signif-

Table 3. Frequency of Current Comorbidities Among Participants of the Study (N = 225) [a, b]

Variables	Autism Spectrum Disorder (N = 164)	Specific Learning Disorder (N = 47)	Intellectual Disabilities (N = 14)	Total (N = 225)
Somatic comorbidities				
Current convulsions	19 (11.6)	6 (12.8)	3 (21.8)	28 (12.4)
Endocrine disease	3 (1.8)	0	2 (14.9)	5 (2.2)
Obesity	40 (24.4)	1 (2.1)	7 (50.0)	48 (21.3)
Visual or auditory deficit	2 (1.2)	0	0	2 (0.9)
Anatomical brain defect	1 (0.6)	0	1 (7.1)	2 (0.9)
Constipation	52 (31.7)	4 (8.5)	7 (50.0)	63 (28.0)
At least one somatic comorbidity	91 (55.5)	11 (23.4)	8 (57.1)	110 (48.9)
Psychiatric comorbidities				
Sleep-Wake disorder	42 (25.6)	5 (10.6)	4 (28.6)	51 (22.7)
Attention deficit ± hyperactivity disorder	32 (19.5)	15 (31.9)	2 (14.3)	49 (21.8)
Oppositional defiant disorder	15 (9.2)	3 (6.4)	2 (14.3)	49 (8.9)
Anxiety and obsessive-compulsive disorders	24 (14.6)	8 (17.0)	2 (14.3)	34 (15.10)
Mood disorder	17 (10.4)	1 (2.1)	2 (14.3)	20 (8.9)
Elimination disorder (enuresis, encopresis)	41 (25.0)	2 (4.3)	5 (35.7)	48 (21.3)
Intellectual disabilities	35 (21.3)	2 (4.3)	*	37 (17.5)
Self-mutilating behavior	6 (6.7)	0	3 (21.4)	9 (4.0)
At least one psychiatric comorbidity	107 (65.2)	28 (59.6)	9 (64.3)	144 (64.0)
Both comorbidities (somatic and psychiatric)	83 (50.6)	8 (17.0)	5 (35.7)	96 (42.7)

[a] Values are expressed as No. (%).
[b] * Core problem.

icant correlation with the type of center after six months of follow-up. This could be because the families who could not afford more expensive services had already left or did not register from the beginning. The characteristics of public and charity centers (busy, long waiting queues, inexperienced and early carrier therapists) could have played a role in low family and child cooperation, leading to rehabilitation dropout.

A paradoxical finding was that the self-reported socioeconomic status of families, including the type of occupation, parental education, family income, and the proportion of families with children headed by single parents, despite previous expectations, was not found to be related to rehabilitation dropout. However, in some western studies, a lower socio-economic level was related to poor adherence (11). Family reluctance to accurately answer income and socioeconomic status and the importance of family "prestige" in the cultural context of our country can be another reason for failure to find the significance of the impact of socio-economic status on rehabilitation problems. After three months' follow-up, family satisfaction with the rehabilitation center was significantly correlated with dropout in the present study, which had the strongest impact on logistic regression analysis (OR = 10.762). This is completely in line with the results of other studies (1, 17). Several other studies reported significant relationships between this variable and rehabilitation dropout (1, 18).

The lack of satisfaction among the families remained to be one of the main predictors of rehabilitation dropout at the end of the six-month follow-up (OR = 4.51). The level of perceived "child cooperation" for rehabilitation was significantly related to dropout (OR = 6.79) at the end of the six-month follow-up. This is consistent with the results of previous studies (1, 17). One of the reasons for this can

Table 4. Multiple Logistic Regression Model Results Regarding Factors Affecting Rehabilitation Dropout (Three Months' Follow-Up)

Variables	OR	P-Value	95% CI for OR	
			Lower	Upper
Type of service center				
Private				
Public	8.24	0.01	2.24	30.32
Charity	5.15	0.02	1.23	21.49
Satisfaction with service delivery				
Satisfied				
Moderate	2.24	0.27	0.52	9.55
Not satisfied	9.36	0.01	2.12	41.37
Severity of developmental disorder				
Mild				
Moderate	4.70	0.02	1.24	17.78
Severe	12.98	0.30	1.27	131.78

Table 5. Multiple Logistic Regression Model Results Regarding Factors Affecting Rehabilitation Dropout (Six Months' Follow-Up)

Variables	OR	P-Value	95% CI for Odds Ratio	
			Lower Limit	Upper Limit
Type of developmental disorder				
Autism spectrum disorder				
Specific learning disorder	6.68	< 0.001	2.85	15.65
Intellectual disabilities	0.67	0.71	0.08	5.48
Satisfaction with service delivery				
Satisfied				
Moderate	2.18	0.17	0.70	6.79
Not satisfied	4.51	0.018	1.30	15.67
Quality of child cooperation with treatment team				
Cooperative				
Medium cooperation	1.16	0.81	0.32	4.10
Not cooperative	6.79	0.017	1.42	32.53

be the exhaustion of children during long-term rehabilitation.

In our study, the presence of sibling and his/her health or illness and the presence of illness in parents were not associated with rehabilitation dropout, while some studies reported the negative impact of these factors (1, 18). This may be due to the presence of a supportive culture and extended families in Iran. The presence of reported comorbid illness in the child, physical or mental, did not have a correlation with rehabilitation dropout in our study. However, this issue has been suggested in some studies as an influential variable (14, 18).

5.1. Conclusions

The findings of this study depicted that 19.3% of families of children with developmental disabilities discontinued rehabilitation after a follow-up period of at least six months. The dissatisfaction of families with the services was correlated with dropout after three and six months. Public and charity types of rehabilitation centers and moderate severity of the developmental disorder, in sequence, had the highest power to predict rehabilitation dropout at the end of the three-month follow-up. In addition, the reported "lack of cooperation" of the child attending the rehabilitation center and the type of developmental disorder, i.e. specific learning disorders, were correlated with

Table 6. Frequency of Effective Factors in Family Decision for Rehabilitation Dropout Based on Open Question (N = 202) [a]

Item Titles	The End of the First Three Months	Between Three and Six Months	Total Six Months
Problems that caused family dissatisfaction			
The cost of rehabilitation was high	15 (68.18)	14 (82.35)	29 (74.36)
No progress was in child's abilities	12 (54.54)	7 (41.17)	19 (48.72)
The trainer did not have the required competencies	8 (36.36)	5 (29.41)	13 (33.33)
The conduct of the trainer and staff was unpleasant	3 (13.63)	5 (29.41)	8 (20.51)
The time assigned to the course was not suitable	2 (9.09)	3 (17.65)	5 (12.82)
The programs were not tailored to the child's abilities	1 (4.54)	3 (17.65)	4 (10.2)
The physical conditions of the center were not suitable	0 (0)	3 (17.65)	3 (7.7)
The higher levels of the centers did not monitor the therapist's work	2 (9.09)	1 (5.89)	3 (7.7)
Other issues			
"We had family problems"	4 (18.18)	6 (35.3)	10 (25.64)
"The child did not need rehabilitation services"	1 (4.54)	3 (17.65)	4 (10.26)
"We moved to another address"	0 (0)	1 (5.89)	1 (2.56)
The total number of rehabilitation items	22	17	39

[a] Values are expressed as No. (%) unless otherwise indicated.

dropout in six months. The most frequent factors reported by parents in their open-ended question about the reasons for dropout showed "high rehabilitation costs", "lack of progress in child's abilities", and "poor competencies of the trainer in the center".

Based on these findings, better financial support to the public and charity rehabilitation services seems to be necessary. Moreover, improving the quality of services through further education of therapists, monitoring their services by technical authorities, and tackling other issues that cause family discontent, especially in charity and public centers, may increase family satisfaction and decrease dropout.

Though the main strength of this study is the prospective data collection that could prevent recall bias, it suffers some limitations. The quality of data, which was mainly based on parents' perceptions and their reservations in sharing data, might have affected the results. Research on higher sample sizes, using a longer-term follow-up with more meticulous sampling and data collection methods, and additional qualitative work are suggested.

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Footnotes

Authors' Contribution: Study concept and design, K.R, MTY, and AR.; Acquisition of data, AR and KR; Analysis and interpretation of data, MRS; Drafting of the manuscript, AR, MTY, KR, RD, MK, and MRS; Critical revision of the manuscript for important intellectual content, MTY, KR, AR, RD, MK, and MRS; Statistical analysis, MRS; Administrative, technical, and material support, AR and KR; Study supervision, KR and MTY.

Clinical Trial Registration Code: This was an observational study and NOT a clinical trial.

Conflict of Interests: None of the authors has any conflict of interest.

Ethical Approval: The study was approved by the Ethics Committee of the Faculty of Medicine, Shahid Beheshti University of Medical Sciences (ethical clearance number IR.SBMU.MSB.REC.1395.216, http://remsp.sbmu.ac.ir/uploads/ethical_transactions_-25.doc).

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