

Delayed Referral in Children with Speech and Language Disorders for Rehabilitation Services

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Objectives: Speech and language development is one of the main aspects of evolution in humans and is one of the most complex brain functions such that it is referred to as one of the highest cortical functions such as thinking, reading and writing. Speech and language disorders are considered as a major public health problem because they cause many secondary complications in the childhood and adulthood period which affect one's socioeconomic status overall

Methods: This study was conducted in two phases. The first phase was to identify all potential factors influencing delay in referral of children with speech and language disorders for receiving rehabilitation services, based on literature as well as the families' and experts' points of view. In the second phase of the study which was designed in a case-control manner, actual factors influencing the time of referral were compared between two groups of participants.

Results: Receiving proper counseling by physicians about importance of the issue had significant impact on the on-time referral for treatment of children with speech and language disorders. After definite diagnosis of speech and language disorders in the child, parents' awareness about the consequences of speech and language disorders had a significant influence on early referral for speech and language pathology services and our hypothesis was confirmed. Discussion: This study highlighted the importance of multiple factors and their relationship with the time of referral, the majority of which were somehow related to one of two major factors: parental awareness and concerns, and physicians' counseling.

Discussion: As described earlier, our study showed that before diagnosis of the child's disorder is definitely given, the physicians' counseling regarding the importance and necessity of early diagnosis, as well as of screening and diagnostic tests play a significant role in the time of referral for receiving speech and language pathology services.

Keywords: Speech and language development, delayed referral, early identification, child, rehabilitation

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Introduction

Speech and language development is one of the main aspects of evolution in humans and is one of the most complex brain functions such that it is referred to as one of the highest cortical functions (1). Good communication skills in children will provide access to other skills and abilities such as decision making, self-confidence and self-esteem, independence, ability to participate in social groups and to successfully communicate with peers (2). Normally, language develops gradually and through a natural process but if this process is impaired for some reason, disorders in speech and language will arise. Speech and language disorders are considered as a major public health problem because they cause many secondary

complications in the childhood and adulthood period which affect one's socioeconomic status overall (3) Speech and language disorders are one of the most common developmental disorders during the first 3 years of life (4). Some underlying causes of speech and language delays include mental retardation, cerebral palsy, hearing loss, autism spectrum disorders and sensory integration disorders (5). However, sometimes no known underlying cause can be determined.

Referral of children who have speech and language disorders to speech and language pathologists for treatment should take place as soon as possible and certainly before the age of language development, i.e., 2-3 years of age. That is called "early" referral (6). The first 36 months of life is a critical period for language

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development. The speed at which language is acquired during this period is never repeated at any other time in life. Early intervention for children with developmental delay in language is crucial and without it, the child's language development will be permanently impaired in comparison to normal peers (7). Various studies in different countries have reported the prevalence rate of speech and language disorders in different groups of children to be 3.2 to 26.2% (8-10). One of the major health challenges facing communities is to generate the knowledge needed to improve the health of children with speech and language disorders in the world. Despite the importance of early diagnosis and intervention for children with speech-language disorders, unfortunately this disorder is actually either not detected or not referred for treatment and rehabilitation at critical ages in many parts of the world and especially in our country, Iran. This may have many different reasons in different societies such as lack of appropriate screening and diagnostic tools or insufficient experts' use of them (11), insufficient knowledge and unfamiliarity of families and professionals about the importance of speech and language disorders.

The aim of this study was to assess the factors contributing to the delayed referral of children with speech and language disorders for rehabilitation. Identification of these factors in every society will be of help to policy makers and executive managers of rehabilitation organizations for identifying and eliminating existing problems which is facing in early diagnosis and intervention.

Methods

This study was conducted in two phases. The first phase was to identify all potential factors influencing delay in referral of children with speech and language disorders for receiving rehabilitation services, based on literature as well as the families' and experts' points of view. In the second phase of the study which was designed in a case-control manner, actual factors influencing the time of referral were compared between two groups of participants: 1) the case group consisting of children "referred over 3 years of age for the first time" or "late referrals" and 2) the control group including children "referred under 3 years of age for the first time" or "early referrals". The sample size in the first phase of the study consisted of 10 experts in the field of language and speech disorders and 15 parents of children with speech and language disorders, and in the second phase of the study 29 children were included in the case and 30 in the

control group, respectively. They were recruited by gradual convenience sampling from Speech and Language Pathology Clinics or Comprehensive Rehabilitation Clinics located on West and South of Tehran city. The participants were allocated to the case and control groups, as described previously. Children with speech and language disorders either in pure form or in combination with other developmental disorders such as autism, cerebral palsy, hearing loss, and mental retardation were included in both case and control groups. Informed consent was acquired from the parents of children who agreed to participate.

In order to carry out the first phase of the study, a rather thorough literature review was conducted on PubMed, Science Direct, Springer, and Google Scholar databases using the keywords such as "early diagnosis", "early intervention", "delayed referral", "developmental screening", "speech and language disorders", "developmental disorders", "developmental delays", "parents' concerns", "at risk children", "prevalence", and "growth and development". Thus, the preliminary list of potential factors influencing the time of referral of children with speech and language disorders for interventions, was prepared. After, in-depth semi-structured interviews were held with 10 experts and specialists in the fields of Speech and Language Pathology, Pediatrics and Otolaryngology, and later with a group of 15 parents of children with speech and language disorders, some of whom were referred for rehabilitation early and some others late. The interviews continued until data saturation occurred. In this way the preliminary list of potential factors contributing to late referrals was modified and finalized. Based on the final list of potential factors contributing to late referrals, a draft version of a questionnaire was produced. Due to the nature of the relevant factors, the questionnaire items were divided into three categories: "factors acting before a definite diagnosis of the disorder were achieved" and "factors acting after a definite diagnosis of the disorder were achieved".

Then the draft version of the questionnaire underwent face and content validity assessment using the Lawsche's method. That content validity index the final form of the researcher-developed questionnaire used in this study was 0/926. In order to evaluate the reliability of the questionnaire the internal consistency of questions was determined by Cronbach's alpha coefficient which was calculated to be equal to 0/81 which represents favorable reliability. This questionnaire contains 58 questions,

18 questions relating to demographic and personal information. Each of the remaining 40 questions that have been designed in Likert style refers to one potential factor influencing the late referral and admission of the child for rehabilitation services. The questionnaire was completed by parents of children in the case and control groups, after which the results in the two groups were statistically compared.

Results

Among the 59 children who participated in the study, 42 subjects were male and 17 were female. To determine significant differences between the case and control groups in terms of the prevalence of each of the potential factors contributing to the time of referral, chi-square test was used and the results are summarized in the table (1).

Table 1. Factors potentially contributing to late referral (Before Diagnosis)

Factors potentially contributing to late referral before diagnosis	chi-square value	significance
<u>Parental awareness</u> about their child's speech and language problems	4.274	0.118
<u>Parental awareness</u> about the natural course of speech and language development in children	6.935	0.031
<u>Parental awareness</u> about the existence of speech and language therapeutic services	4.264	0.234
Having received <u>proper counseling by physicians</u> about the importance and necessity of early diagnosis of speech and language problems in children	5.978	0.05
Having received <u>proper counseling by physicians</u> about screening tests for children's speech and language delays	8.414	0.015
Having received <u>proper counseling by physicians</u> about diagnostic tests for hearing impairment in children	8.586	0.014
Parents' concerns about their child's disorder being unfold to relatives and family	11.340	0.003
Parents' denial of warning signs of speech and language delay in their child	2.979	0.226
Existence of other priorities in the life of parents	4.402	0.111
The extent of parents' concerns about speech and language disorders in the global health of their child	1.082	0.582
Having received guidance from other professionals about the importance and necessity of early diagnosis of speech and language problems in children	4.025	0.134

Tables (1), (2) and (3) demonstrate each factor potentially influencing delay in referral of children with speech and language disorders for receiving rehabilitation services the results of statistical

comparison between the case and control groups in terms of the potential factor. The first two tables include factors acting before diagnosis and after diagnosis, respectively.

Table 2. Factors potentially contributing to late referral (After diagnosis)

Factors potentially contributing to late referral after diagnosis	chi-square value	significance
<u>Parental awareness</u> about the effects of speech and language disorders in the child's life	16.588	0.001
Parents' concerns about their child's disorder being unfold to relatives and family	6.283	0.043
Parents' denial of warning signs of speech and language delay in their child	8.376	0.015
Existence of other priorities and in the life of parents	9.319	0.025
The extent of parents' concerns about speech and language disorders in the global health of their child	54.999	0.000
Parental beliefs about the possible spontaneous recovery of speech and language disorders	11.300	0.004
The extent of parents' confidence in the effectiveness of speech and language therapeutic interventions	6.013	0.111
Having received proper counseling from physicians about referral to speech therapy services	5.270	0.072
Having received guidance from other professionals about the existence of speech and language therapeutic services	5.474	0.065
Accessibility to speech and language pathology service providers	1.425	0.490
Accessibility to related specialists' offices	2.445	0.294

Table 3. Demographics factors potentially contributing to late referral

Demographics factors potentially contributing to late referral	chi-square value	significance
existence of other associated disorders	9.728	0.021
Accessibility to speech and language pathologists	1.425	0.490
Accessibility to offices of related specialists'	2.445	0.294
Education level of mother	7.507	0.111
Education level of father	5.976	0.201
Mother's employment status	6.777	0.034
Father's employment status	0.01	0.920
Family income	8.101	0.088
The severity of the child's speech and language disorder.	0.553	0.758
Marital Status of parents	0.001	0.999
Insurance coverage	1.565	0.211
	2.474	0.116

As can be seen in table (1), “having received proper counseling by physicians” in terms of the importance and necessity of early diagnosis, as well as of screening and diagnostic testing is the most frequent significantly different factor between the case and control groups of children before definite diagnosis of speech and language disorders is provided. In other words, in all three terms, “physicians’ proper counseling” plays a significant role in the time of referral. “Parental awareness” is significantly different between the two groups of children, only in terms of the natural course of speech and language development. “Awareness” about the child’s speech and language problems, as well as about the existence of speech and language therapeutic services is not significantly different between the two groups, and thus does not seem to play an important role in time of referral. “Parents’ concerns about the child’s disorder being unfold to relatives and family” is another factor significantly contributing to the time of referral.

As Table (2) demonstrates, after definite diagnosis of the child’s disorder is provided, the most frequent significantly different factors between the case and control groups are those somehow relating to the parents: parental awareness about the effects of speech and language disorders in the child’s life, parents’ concerns about their child’s disorder being unfold to relatives and family, parents’ denial of warning signs of speech and language delay in their child, the extent of parents’ concerns about speech and language disorders in the global health of their child, parental beliefs about the possible spontaneous recovery of speech and language disorders, and parents’ other priorities in life. Unlike the time frame before definite diagnosis of the child’s disorder was given, in this period of time having received physicians’ counseling about referral to speech therapy services or guidance from other professionals about the existence of speech and language therapeutic services, does not show significant difference between the two groups and thus does not seem to contribute significantly to the time of referral. Existence of other associated disorders in the child is another factor playing a significant role in the time of referral.

Table (3) indicates that the only demographic factor significantly different between the two groups is the mother’s employment status. In fact, the children of employed mothers were significantly referred earlier than those of non-employed mothers.

Discussion

As described earlier, our study showed that before diagnosis of the child’s disorder is definitely given, the physicians’ counseling regarding the importance and necessity of early diagnosis, as well as of screening and diagnostic tests play a significant role in the time of referral. Our results are consistent with the results of a study carried out in the years 2002-2004 in Montreal, Canada by Armen Feldman et al., who found that certain factors related to physicians can cause delays in receiving effective treatment and rehabilitation for children with developmental delays, such as lack of understanding of the severity of the disorder, and inability to accurately diagnose developmental delays, or doubts on the effectiveness of rehabilitation (12). Also in a study conducted by Bailey et al. at the University of North Carolina, pediatricians’ reluctance and failure to refer young children or those with mild abnormalities for early intervention, and failure to use and interpret tests and standard tools for developmental and behavioral screening were considered as important factors influencing the time of admission of children with various developmental disorders for receiving early interventions (13). These findings are consistent with our findings regarding the importance of the physicians’ role in this issue. However, it is noteworthy that our results show the physicians’ counseling role is not as important in the time of referral after definite diagnosis of the child’s disorder is provided. It may be that the several other factors acting after definite diagnosis, most of which are related to the parents, are so powerful they overshadow the effect of the physicians’ counseling on the time of referral. To our knowledge, no other studies have reported similarly.

As previously reported in the Results section, after definite diagnosis of the child’s disorder is provided, the most frequently encountered significantly different factors between the case and control groups are those somehow relating to the parents. “Parental awareness about the effects of speech and language disorders in the child’s life” is one of those factors. This finding is consistent with the results of Leatherman et al. in 2004 who reported that increase in parents’ knowledge about developmental disorders was one of the most effective strategies for early identification and intervention (14). Also, we found that before definite diagnosis of the child’s disorder, “parental awareness about the natural course of speech and language development in children” was significantly different between the

case and control groups and thus played an important role in the time of referral. So was the “parents’ denial of warning signs of speech and language delay in their child” and “the extent of parents’ concerns about speech and language disorders in the global health of their child”, after definite diagnosis of the disorder, these two latter factors somehow dealing with the parents’ level of knowledge and awareness too. These results are concordant with the results of Bailey et al. in 2004 who considered lack of parents’ information about the signs and symptoms of developmental disorders as one of the factors contributing to late referral for early intervention (13). However, it has to be noted that two other factors relating to awareness, that is, “parental awareness about their child’s speech and language problems” and “parental awareness about the existence of speech and language therapeutic services” did not differ significantly between the two groups. The possible reason may be that before definite diagnosis, that is, when the parents have not yet been confronted with the painful fact about their child’s disorder and the situation is not quite tangible for them, not all themes for awareness result in a significant difference in the time of referral.

According to findings of the present study it was identified that after receiving a definite diagnosis of their child’s speech and language disorder, the “existence of other priorities in the life of parents” played a significant role in the late referral for treatment. A very similar result was reported by Bailey et al. in 2004 who considered that one of the possible reasons for the lack of on-time referral to receive early interventions was the “existence of other priorities and concerns in the life of parents” (13). As mentioned in the Results section, in the present study none of the demographic factors studied were significantly different between the case and control groups, except for the employment

status of the mother. However, many other studies have shown the influence of certain demographic factors on the time of referral of developmental disorders for intervention. For example unlike the results of our study, in a study conducted in Montreal, Canada by Feldman et al. it was shown that the economic situation of families who have children with developmental disorders had a large impact on receiving on-time interventions (12). The same study reported that convenient accommodation and easy access to services had a large impact in the referral time. This was not true about our results which showed that accessibility to speech and language pathologists, as well as accessibility to offices of related specialists did not contribute to the time of referral.

Unlike our results, in another study carried out by Guarino et al. the ratio of girls with developmental disorders who were identified late was reported to be higher than boys. Guarino suggested that sexual discrimination may be the explanation (15). This finding was discordant with ours. The study of Guarino et al. also showed that families with low income and low literacy experience more difficulties in accessing health services (15). According to our none of the two factors played a significant role in on-time referral for receiving speech and language pathology services.

Conclusion

This study highlighted the importance of multiple factors and their relationship with the time of referral, the majority of which were somehow related to one of two major factors: parental awareness and concerns, and physicians’ counseling.

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