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INVESTIGATING ENROLLMENT AND CONTINUITY OF PARENTS TO EARLY CHILDHOOD INTERVENTION SERVICES

EBEVEYNLERİN ERKEN ÇOCUKLUKTA MÜDAHALE HİZMETLERİNE KATILIMLARININ VE DEVAMLILIKLARININ İNCELENMESİ

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ABSTRACT

Early childhood intervention (ECI) services are recognized as the fundamental right of children and their parents under "The Geneva Declaration of the Rights of the Child". Although the importance of early intervention services is well known, there are still some issues regarding the enrollment of parents. The aim of the study is to examine the enrollment of the parents who are directed/invited to ECI service. The enrollment of parents into two different ECI projects (one including neuro-developmentally high-risk group and another including neuro-developmentally low-risk group) executed in 2018-2019 was examined. The reasons for the parents who rejected to enroll the ECI service were recorded. The reasons for the parents who left ECI services were examined. Finally, it was examined why the parents missed their therapy sessions. Seventy-two (69.9%) parents out of 103 of the low-risk group and 53 (96.3%) parents out of 55 of the high-risk group accepted to participate in the study. Parents who rejected to enroll in ECI usually cited the difficulties of transportation and taking a day off. Respiratory Distress Syndrome (p=0.027) and distance to the center (p=0.048) significantly affect parents' continuity of the ECI in low risk group. The distance to center (p=0.008, r=371) and multiple pregnancies (p=0.008, r=314) significantly correlate with not being able to attend to therapy sessions. The study examined the barriers which limited the access to ECI services. It is important to mention that most of these factors are reversible.

Keywords: developmental disabilities, early intervention, family-centered practice, maternal-child health services, parent enrollment.

ÖZ

Erken çocukluk müdahale (EÇM) hizmetleri, "Cenevre Çocuk Hakları Bildirgesi" kapsamında çocukların ve ebeveynlerinin temel hakkı olarak kabul edilmektedir. Erken müdahale hizmetlerinin öneminin iyi bilinmesine rağmen, ebeveynlerin katılımında halen bazı sorunlar bulunmaktadır. Çalışmanın amacı, EÇM hizmetine yönlendirilen / davet edilen ebeveynlerin katılımlarını incelemektir. Çalışmada 2018-2019 yıllarında yürütülmüş iki farklı erken müdahale projesine ebeveynlerin katılımları incelenmiştir. Erken müdahale hizmetine katılmayı reddeden ailelerin gerekçeleri kaydedilmiştir. Erken müdahale servisini yarıda bırakan ebeveynlerin ayrılma nedenleri incelenmiştir. Son olarak, ailelerin terapi seanslarını neden kaçırdıkları incelenmiştir. Düşük risk grubunda yer alan 103 ebeveynin 72'si (%69,9) ve yüksek risk grubunda yer alan 55 ebeveynin 53'ü (%96,3) çalışmaya katılmayı kabul etmiştir. Erken müdahale programına katılmayı reddeden ebeveynler genellikle ulaşım ve iş yerinden izin alma sorunlarını gerekçe göstermişlerdir. Düşük riskli grupta Respiratuar Distres Sendromu (p=0,027) ve merkeze uzaklık (p=0,048) ebeveynlerin EÇM devamlılıklarını anlamlı bir şekilde etkilemektedir. Düşük riskli grupta merkeze uzaklığın (p=0.008, r=371) ve çoğul gebeliğin (p=0.008, r=314) terapi seansına katılamama ile anlamlı bir şekilde ilişkili bulunmuştur. Bu çalışma, ebeveynlerin erken müdahale hizmetlerine erişimini kısıtlayan engelleri incelemiştir. Tespit edilen faktörlerin çoğunun değiştirilebilir olduğunu belirtmek önemlidir.

Anahtar kelimeler: gelişimsel engellilikler, erken müdahale, aile merkezli yaklaşım, anne-çocuk sağlığı hizmetleri, ebeveyn katılımı

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INTRODUCTION

In article number 3 of the United Nations Convention on the Rights of the Child, it is emphasized that in all actions concerning children the best interests of the child shall be a primary consideration and the states undertake to ensure the child such protection and care shall take all appropriate legislative and administrative measures (UNICEF, 1989). In addition to the rights in this convention, articles in Part C of Individual with Disabilities Educational Act (IDEA) approved by the United States Congress in 1986 for children with a disability has also inspired other countries. The aim of the IDEA is to enhance the development of infants and toddlers with disabilities, reduce educational costs through early intervention, maximize independent living, and enhance the capacity of parents (IDEA, 2004).

While some countries require a certain diagnosis or developmental delay for providing early childhood intervention (ECI) such as England, some other countries like Portugal initiate ECI if babies or their parents have risk factors (VETforEI, 2019; Zigler & Valentine, 1979). In Turkey babies at risk had been allowed to access early intervention services free of charge with a certain diagnosis until 2019. The new early intervention reporting system called ÇÖZGER was launched in 2019 (Çözger, 2019). With this system, babies at risk are offered to benefit ECI services free of charge even without a certain diagnosis. The early intervention support system procedure starts with the obtainment of medical and educational reports. Following obtainment of the reports, parents and their babies can receive developmental support for 8 sessions per month from the Special Education and Rehabilitation Centers free of charge. With this new system, it is predicted that more babies and their parents will apply to ECI services. Parents of babies at risk should apply individually in order to receive services for ECI. There is no mechanism to direct families to participate in the early intervention system. Therefore, the importance of parental awareness in early intervention services becomes very important (Karadavut et al., 2018).

There are important aspects of ECI services. The collaboration of parents and professionals in early intervention is very important for the effectiveness and continuity of the practices (Dunst, 1997). For the encouragement of enrollment and continuity of the parents in early intervention programs, different models such as clinic-based, family-centered, and home visiting have been developed (Guralnick, 2005; McWilliam, 2010). Seven key principles have been published in order to include the parents in the early intervention system and ensure their active participation (Eurlyaid, 2019).

- First key principle is that children of the parents who have the necessary support and possibility can assure an increase in learning and development. This support may include not only expert consultations but also social and economic well-being.
- Secondly, the progress which could be achieved through early childhood intervention is individual and variable according to preferences, learning styles of children, and the cultural beliefs of their parents.
- Interventions with young children and their parents must be based on formal sources such as validated practices, laws, and regulations.
- It is necessary to consider that children and parents identify the needs and priorities by themselves in the early intervention service.
- Within early childhood intervention there should be a case mediator. The first role of the case mediators in early childhood intervention is to work together and support parents and caregivers.
- The best way to learn something in a natural context is through the daily experiences and interactions for babies and toddlers.
- The case mediator directs the families about their priorities, needs, and interests (Eurlyaid, 2019).

The practices support the well-being of infants at risk and their parents are called early intervention programs. Although the importance of early intervention programs in early childhood is emphasized more and more every year, some parents may not accept developmental support. On the other hand, providing early intervention services have some limitations as; the awareness level of healthcare professionals about the early intervention might be low, parents may not realize that their babies need developmental support and there is not a certain pathway for including healthcare professionals and parents in the service (Twardzik, MacDonald, & Dixon-Ibarra, 2017). The economic, social, and cultural beliefs are also factors that affect enrollment in the early intervention system. Health and well-being might have different meanings for the people living in different cultures.

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It is expected for early intervention systems to differ in the social structures and economic characteristics of different societies (Rosenberg, Zhang, & Robinson, 2008). In the countries where early intervention is not a routine, the concerns of society affect the enrollment of parents (Jimenez et al., 2014). The studies have shown that living in rural areas, low income, and low education levels decrease enrollment of parents in the early intervention system (McManus, McCormick, Acevedo-Garcia, Ganz, & Hauser-Cram, 2009). The parent reports show that the race, young maternal age, low level of education, not being able to speak the local language of the place of residence, and financial reasons are the causes of not participating in the early intervention service (Clements, Barfield, Kotelchuck, Wilber, & journal, 2008; Peterson et al., 2004). In Turkey, with the new medical reporting system for babies at risk, a rise in ECI service referral is foreseen. In order to make early intervention services accessible, there is a need to examine the attitudes of enrollment of parents. With this perspective, the main aim of the current study is to investigate the enrollment of parents in early intervention services according to their babies' developmental risk levels. The second aim of the study is to analyze the reasons for parents who withdraw from early intervention services. The third aim of the study is to examine the continuity of parents to the therapy sessions provided within the scope of the projects.

METHOD

Sample Group

The enrollment of parents in two different ECI projects was examined between 2018 and 2019 at the TSÇV Family Counseling Center. In one of these projects, parents of premature babies which were born under 33 weeks, younger than six months corrected age, and have a low risk for cerebral palsy were invited. In the second project, parents of children under the age of 3 who have a high-risk for cerebral palsy such as abnormal neurological examination or cranial imaging findings were invited. In order to create a more homogeneous participant group, babies with genetic and metabolic diagnoses were excluded from the studies. Pediatric neurologists and neonatal intensive care professionals in the surrounding hospitals were informed of the referral of parents of babies who are convenient for the study.

Data Collection Tools

The parents in the low-risk groups were directed by physicians and invited by phone, while the parents in the high-risk groups were only directed by physicians. The biological, social, and environmental factors of parents and their babies were recorded at the first appointment. The socio-demographic scale, parents' ages, educational levels, professions, consanguinity, and income levels were recorded through parental reports. The biological risk factors of babies were obtained from medical reports. The excuses of the parents who refused to participate in ECI services were questioned and recorded. The parents from the low-risk group were called and invited to the study with the following invitation text.

Invitation Text: The invitation text for the parents of babies in low-risk group

"I am calling you through your doctor's direction to the early intervention service. We have an early intervention program that we follow the development of premature babies for 6 months for free. In this program, you will be able to get information about the development of your baby. You will have professional support to ask all the questions you wonder about the development of your baby. We have a sterile room where only babies at risk can enter. There is no blood collection or imaging method. Our only request is for you to attend the scheduled appointments regularly for six months."

If parents refused to participate in the project they were asked for their excuses with the question of "We invited you to enroll ECI service free of charge. You declared that you don't want to enroll for the service. Would you please give us your reasons why you don't want to enroll for the service? In this way we can improve our ECI service.". The appointments in the low-risk group were organized by three physiotherapists while the secretariat department of TSÇV Family Consultation Center followed the appointments in the high-risk group.

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While organizing appointments for the parents who agreed to participate in the project, the following criteria were taken into consideration.

- Parents were asked whether they want to come on weekdays or weekends.
- Whether they preferred specific visiting hours.
- They were reminded by messages or phone calls before all their appointments.
- Appointments were reorganized for the nearest possible dates if parents have hospital appointments, vaccination appointments, and any health issues.

Data Analysis

All analyses were performed using IBM SPSS Statistic Version 14. The baseline demographics and the views of parents who refused to participate in the study were given with frequencies and percentages. The relation between demographics and continuity of parents in the study were tested by Wilcoxon rank-sum analysis (Perolat 2015). The relation between the cited obstacles of the parents and their continuity to therapy sessions were examined with Spearmen Correlation (Myers, 2004). The effect size was computed differences between completed and dropout groups. Hedges g was interpreted as 0.2 ≥ small effects, 0.5 ≥ medium effects, 0.8 ≥ large effects (Lakens, 2013).

RESULTS

In the neuro-developmentally low-risk group, 103 parents were invited to the project between May 2018 and November 2019. Seventy-two (69.9%) parents agreed to enroll in the project while 12 parents (11.6%) enrolled but later on dropped out of the project. The corrected mean age of the babies was 1.5 months (min:0 months, max:4 months, 37 boys 51.4%, 35 girls 48.6%). In the neuro-developmentally high-risk group, 53 out of 55 parents of babies which were referred between January and December 2019, agreed to enroll, while three parents enrolled but later on dropped out of the project. The average corrected age of babies in the high-risk group was 9.6 months (min:0 months, max:22 months, 29 boys 52.7%, 28 girls 47.3%). The highest percentage of the reasons why parents refused to enroll in the project is the transportation problem. The highest percentage of the reasons why parents drop out of the project are issues regarding taking a day off. All the reasons why parents refused to enroll and dropped out of the project are listed in Table 1.

*This research had been submitted in NATO women officers meeting in Turkey Harbiye.

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Table 1. *The Reasons Why Parents Refused to Enroll and Dropped Out of the Project*

	Low-risk group		**High-risk group**	
	Refused to enroll in the project (n=31) Frequency (Percentage)	Dropped out (n= 12) Frequency (Percentage)	Refused to enroll in the project (n= 2) Frequency (Percentage)	Dropped out (n= 3) Frequency (Percentage)
Transportation problem	11(35%)	5(41%)	0	0
No given reason	9(29%)	1(8%)	0	0
Cannot get a day off	4(12%)	3(25%)	0	0
The risk of infection	3 (9%)	3(25%)	0	0
Do not have a need for early intervention program	3 (9%)	0	2(100%)	0
Moving out of town	1 (3%)	0	0	3 (100%)

Sixty parents (88.2%) completed the project in the neuro-developmentally low-risk group and 50 (94.3 %) parents completed in the neuro-developmentally high-risk group. Demographic characteristics and the distance between the place of residence and the center of the parents who completed and dropped out of the project of low-risk babies are shown in Table 2.

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Table 2. *The Socioeconomic Level of Parents, Environmental Conditions, and Biological Factors of Low-Risk Babies Who Completed and Dropped Out of the Project*

	Completed (n:60) M (SD) (min-max)	*Dropped Out (n:12) M (SD) (min-max)*	*p-value*	*Effect Size (Hedges' g)*
Birth week (gw)	29.3 (1.9) (24-32)	29.4 (2.4) (25-32)	0.621	0.04
Birth weight (gr)	1287 (377.8)(540-2170)	1385 (608.8) (830-2860)	0.918	0.24
Stay NICU (days)	54.8 (31.8) (14-150)	51.2 (29.9) (14-110)	0.565	0.14
RDS (%)	81	50	**0.027**	**0.73**
The education level of the mother (year)	10.4 (4) (5-18)	12.2 (5.4) (5-23)	0.220	0.24
The education level of the father (year)	10.9 (3.7) (5-17)	13.4 (7.5) (5-32)	0.223	**0.53**
Distance to the center (km)	17.7 (14) (3-90)	24.8 (26) (3-55)	**0.048**	**0.52**
Parental income (Multiplication of minimum wage)	2.7 (1.7) (1-10)	4 (3)(1-11)	0.173	**0.64**

NICU: Neonatal Intensive Care Unit, RDS: Respiratory Distress Syndrome

An average of 7.3 sessions was planned in six months in the low-risk group and an average of 5.1 of the planned sessions took place. In the high-risk group, an average of 41 of the 51.4 sessions planned was held. The distance between the center and their place of residence (p=0.008, r=371) and multiple pregnancies (p=0.008, r=314) were found significantly correlated with not attending to the therapy sessions. The reasons cited by parents for not being able to attend the sessions were infections (50%), not being able to get a day off (27.2%), being out of town, having holidays (9%), other health issues related appointments (9%) and multiple pregnancies ((parents who had twins or triplets needed help to come to the center) 4.8%).

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DISCUSSION

The first years of life are unique as they provide learning opportunities in a way that it never happens later (Krägeloh-Mann, Lidzba, Pavlova, Wilke, & Staudt, 2017). On the other hand, babies are quite vulnerable to adverse stimulations in the same age generation (Walker et al., 2007). Early intervention gives a chance to reduce the adverse conditions in the natural environment of the baby and enrich positive stimulations to support her/his development. Although researchers have accepted the importance of early intervention services, some difficulties may be experienced in delivering early intervention services to parents (Rosenberg, Zhang, & Robinson, 2008).

In our study, 69.9% of parents in the low-risk group and 96.3% in the high-risk group were accepted to enroll in the early intervention program. A cohort study took place in California has shown that enrollment rate was 76% at high risk babies (Hintz et al., 2019). The enrolment rate of the mentioned study is less than our sample for high risk babies. The high enrollment rate of high-risk families might be related to their anxiety level. Similarly, it has been shown in the literature that doctors tend to refer to early intervention programs for high-risk babies more frequently. Also, the parents' views about the developmental status of their baby affect positively their enrollment in the early intervention service (Heinrichs, Bertram, Kuschel, & Hahlweg, 2005).

It has been seen that the awareness of experts and parents about developmental monitoring in the low-risk group was insufficient (Carman et al., 2017). A survey study with pediatricians showed that parents who have preterm babies were hesitant about participating in early intervention services (Heinrichs, Bertram, Kuschel, & Hahlweg, 2005). It has been seen that planned behaviors, motivational factors, and the transtheoretical model were effective while the parents give their decisions (Jimenez et al., 2014). In accordance with the literature, we found that low-risk groups enroll less than the high-risk groups in the early intervention program.

In our study, 70% of the parents refused to enroll in ECI due to issues of transportation. These parents stated that they would like to benefit from the ECI service if it is implemented at home or in a center which is within walking distance. It was emphasized in previous studies that the parents who live in rural areas with low income, low education levels, and less knowledge on health have less enrollment in early intervention support (Jimenez et al., 2017). Some countries have initiated home-based support practices to increase participation in early intervention support (Silva et al., 2020).

We examined why parents dropped out of the project in the low-risk group. Totally, 11.7% of parents dropped out of the project in the low-risk groups. We found that Respiratory Distress Syndrome (RDS) has a statistically significant positive effect and distance to the center has a statistically significant negative effect on the completion of ECI project. The RDS has an adverse effect on the baby's neuro-development (Hoobler et al., 2010). The higher the concern level of the parent gets the more enrollment rate of parents in ECI is. While the parents who completed the project were living an average of 17.7 km from the center, the parents dropped out of the project were living 24.8 km away on average. Parents who dropped out of the project listed transportation issues, not being able to take a day off, and the risk of infections as reasons. Similarly, a study showed that transportation opportunities were important factors for participation in the early intervention program (Almsbhieen, 2016). In our study, parents who dropped out of the project had higher income and education levels than those who continued to the project. Parents with higher levels of income may have left the project due to their higher chance to access information and special ECI opportunities.

We also examined the therapy session participation of parents who continued to the project. The distance of the center and multiple pregnancies were found statistically significant with not being able to participate in therapy sessions. Parents who have twin and triplet babies stated that in addition to the mother and father, one more person should accompany them to their appointments, otherwise, they have difficulties. Similarly, the literature has shown that the time constraints, childcare needs, and transportation problems as structural barriers in the parents' enrollment in the early intervention program (Lamb-Parker et al., 2001; Spoth, Redmond, Trudeau, & Shin, 2002).

Babies with developmental risks such as premature birth have more visits to the doctor in the first year of life. They have additional controls in the fields of eye, ear, neurology, and neonatology besides routine vaccines

and controls (Cuevas et al., 2005). Therefore, it may be difficult to find suitable dates and times for both specialists and the family while setting a therapy session. The participation rates at planning sessions of the families who continued therapy were 69% and 79% in the low and high-risk group in our study. We found that multiple pregnancy and distance to the center were found statistically significant in order not to participate in the therapy sessions.

The fact that ECI services are not yet widespread in the national system may negatively affect parents' awareness of the importance of early intervention. As the ECI projects were conducted in the context of two different randomized controlled trials, parents may have felt insecure to enroll in the ECI service. Another limitation of the study is that the projects were driven in a metropolitan city. The enrolment rates and reasons of rejection in early intervention programs in rural areas may be different.

CONCLUSIONS AND RECOMMENDATIONS

As we known this is the first study to investigate the enrollment attitudes of parents of babies at high-risk and low-risk to ECI services in Turkey. Almost all parents of babies at high risk enrolled in ECI. Parents of babies at low-risk refused to participate the invitation because they thought they would have issues with transportation and not being able to get a day off. Parents who dropped out of the project in the low-risk group similarly cited issues with transportation, being able to take a day off, and the risk of infection. In the low-risk group, it has been shown that the distance of families to the ECI center significantly negative affects their participation attitudes. It has been shown that in families who can not attend their therapy sessions regularly, multiple pregnancies and their distance from the center significantly affect their enrollment attitudes.

The importance and advantages of early intervention should be well explained to the public. Awareness and in-service training should be provided for experts who work in pediatrics about the importance of early intervention and how developmental monitoring should be done.

The accessibility of early intervention programs should be facilitated especially for multiple pregnancies, parents living in rural areas, and low-income groups. In order to increase accessibility, options such as dissemination activities, home-based, or center-based services, transportation support, or travel fee support should be considered. In cases where there is a high risk of infection or re-hospitalization, priority should be given to home-based practices.

The appointment planning process should be dynamic in early intervention services. While organizing therapy sessions, the unique characteristics of parents, other physician appointments, and the days that they can get permission from work should be taken into consideration. The communication between parents and the early intervention staff should be flexible and fast. The necessary legal arrangements should be made to obtain permission from the workplace for the employees with babies at risk.

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