

Research Article

Retrospective examination of home healthcare services applications in a children's hospital

Bir çocuk hastanesinde evde sağlık hizmetleri başvurularının retrospektif incelenmesi

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Abstract

Introduction: The purpose of the present study was to examine the descriptive data regarding the children, their families, and living conditions in the records of home healthcare services provided for children between 01.04.2020 and 01.04.2021 at a children's university hospital.

Methods: The sample of this descriptive study consisted of the files of 170 pediatric patients who received service from Health Sciences University (SBU) Izmir Dr. Behçet Uz Pediatric Diseases and Surgery Training and Research Hospital Home Healthcare Services Unit between 01.04.2020 and 01.04.2021. The data were collected with the Data Record Form that was created by the researchers in line with the contents of the files kept for patients. The analysis of the data in this form was made in the SPSS package program 25.0 trial version. The data were described in terms of numbers, percentages, and averages, and the Chi-Square Significance Test was used in the comparisons made between the demographic data. The statistical significance level was considered as $p < 0.05$. To conduct the study, permission was obtained from the Ethics Committee of S.B.U. Izmir Dr. Behçet Uz Pediatric Diseases and Surgery Training and Research Hospital.

Results: The children who were included in the study were between the ages of 0 and 17 and the average age was 9.11 ± 4.61 . It was found that a total of 54.7% of the children were male, 97.6% were cared for by their mothers, 61.8% of the children whose files were examined had social security at the Social Security Institution (SSI), 51.8% were receiving service from the unit and were diagnosed with a neurological disease, and 58.8% were fully dependent in their daily living activities, 27.1% of them used mechanical ventilation, 37.6% used aspirator devices, 37.1% needed Oxygen (O₂) support, 48.7% were fed orally, 27.7% were fed through the nasogastric route, and 23.6% were fed through Percutaneous endoscopic gastrostomy (PEG) and 4.2% of the participating children developed pressure sores. According to the records regarding the physical conditions of the places where children lived, 72.4% lived in apartments, 38.8% had a house that was heated by a heating system natural gas, 98.8% had good lighting in their homes, and 57.1% had alaturka toilet in their homes. Also, 64.8% of the children stayed in the living room of the house and 92.4% had good home hygiene. A statistically significant difference was detected between the income status of the children's families and their social security ($X^2 = 47.542$ $p = 0.001$, $df = 1$).

Conclusion: The factors such as the majority of patients registered to home healthcare services being cared for by their mothers, their high rates of dependency in daily living activities, some developing pressure sores, the need to be attached to a medical device, and varying home conditions in suitability for care show that patients have varying medical, psychological and social needs. For this reason, it would be beneficial to focus on pediatric studies in home healthcare services, organize.

Keywords: Children, home care, chronic disease

Öz


Giriş: Bu araştırmanın amacı, bir çocuk üniversite hastanesinde 01.04.2020 - 01.04.2021 tarihleri arasında çocuklara yönelik sunulan evde sağlık hizmetleri kayıtlarında yer alan çocuk, aile ve yaşam koşullarına ilişkin tanımlayıcı verilerin incelenmesidir.

Yöntem: Tanımlayıcı tasarımdaki çalışmanın örneklemini, Sağlık Bilimleri Üniversitesi (SBÜ) İzmir Dr. Behçet Uz Çocuk Hastalıkları ve Cerrahisi Eğitim ve Araştırma Hastanesi Evde Sağlık Hizmetleri Birimi'nden 01.04.2020 - 01.04.2021 tarihleri arasında hizmet alan 170 çocuk hastanın dosyasından oluşturmaktadır. Veriler, hastalar için tutulan dosya içeriğine doğrultusunda araştırmacılar tarafından oluşturulan veri kayıt formu aracılığı ile toplanmıştır. Bu formdaki verilerin analizi SPSS paket programı 25.0 deneme sürümünde yapılmıştır. Veriler sayı, yüzde ve ortalamalar üzerinden tanımlanmış, demografik veriler arasındaki karşılaştırmalarda ki-kare önemlilik testi kullanılmıştır. İstatistiksel anlamlılık düzeyi $p < 0.05$ olarak ele alınmıştır. Araştırmanın uygulanabilmesi için S.B.U İzmir Dr. Behçet Uz Çocuk Hastalıkları ve Cerrahisi Eğitim ve Araştırma Hastanesi Etik kurulundan izin alınmıştır.

Bulgular: Araştırma kapsamına alınan çocuklar 0-17 yaş arasında olup, yaş ortalaması $9,11 \pm 4,61$ 'dir. Çocukların %54,7'sinin cinsiyeti erkektir ve %97,6'sının bakımı anneleri tarafından yapılmaktadır. Dosyası incelenen çocukların %61,8'inin Sosyal Güvenlik Kurumu (SGK) sosyal güvencesi bulunmaktadır. Birimden hizmet alan çocukların %51,8'inde nörolojik hastalık tanısı bulunmakta olup, %58,8'u günlük yaşam aktivitelerinde tam bağımlıdır. Çocukların, %27,1'inin mekanik ventilatör, %37,6'sının aspiratör cihazı kullandığı, %37,1'inde Oxygen (O₂) desteğine ihtiyacı olduğu görülmektedir. Çocukların %48,7'si oral, %27,7'si nazogastrik ve %23,6'sı ise Perkütan Endoskopik Gastrostomi (PEG) ile beslenmektedir. Katılan çocukların %4,2'sinde baskı yarısının gelişmiş olduğu görülmektedir. Çocukların yaşadıkları yerlerin fiziksel koşullarına ilişkin kayıtlara göre, %72,4'ünün apartman dairesinde oturduğu, %38,8'inin ısıtma sisteminin doğalgaz ile ısındığı, %98,8'inin evlerinde iyi aydınlanma, %57,1'sinin evlerinde alaturka tuvalet bulunmaktadır. Çocukların, %64,8'inin evin salonunda kaldığı, %92,4'ünün ev hijyeninin iyi olduğu belirlenmiştir. Çocukların ailelerinin gelir durumları ile sosyal güvencesi olması arasında istatistiksel olarak anlamlı bir farklılık saptanmıştır ($X^2 = 47.542$ $p = 0.001$, $df = 1$).

Sonuç: Evde sağlık hizmetlerine kayıtlı hastaların çoğunluğuna annelerinin bakması, günlük yaşam aktivitelerinde bağımlılık oranlarının yüksek olması, bazılarında baskı yarısının gelişmiş olması, tıbbi cihaza bağımlılık ihtiyacının olması, ev koşullarının bakıma uygunluğunun değişiklik göstermesi gibi faktörler hastaların çeşitlilik gösteren tıbbi, psikolojik ve sosyal ihtiyaçlarının olduğuna işaret etmektedir. Bundan dolayı evde sağlık hizmetlerinde pediatrik çalışmalara ağırlık verilmesi, bu alanda hizmet sunanlara yönelik eğitim programı açılması, hizmet sunumunda kayıtlardaki bu veriler dikkate alınması yararlı olacaktır.

Anahtar Kelimeler: çocuk, evde bakım, kronik hastalık

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	https://doi.org/10.22391/fppc.1325025			

Key Points

1. It was determined that the majority of children who were registered to home healthcare services were cared for by their mothers and their dependency rates were high in terms of daily life activities.
2. Most of the children lived in apartments and stayed in the living room of their houses.
3. A statistically significant result was detected between the income status of the families of the children and their social security status.

Introduction

Home healthcare services increase the survival of individuals, reduce morbidity, improve the quality of life by improving their self-care, reduce their dependence on the environment, and reduce bed occupancy and the risk of infection [1]. With the decrease in hospitalizations, healthcare expenses decrease, and physical and psychological comfort of terminal patients is provided. Home healthcare services are important for these reasons [2].

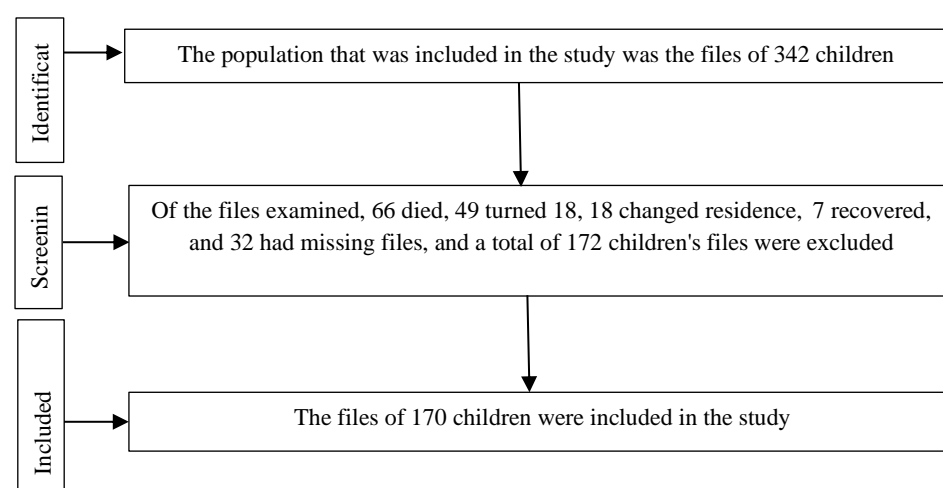
Home healthcare services require continuous protective, therapeutic and rehabilitative services not only for the elderly, but also for children and families in need [2]. Although children in need of home health services comprise <1% of all United States (US) children, they account for an estimated 30% of all pediatric health care costs, 56% of hospitalized patients, 82% of hospital days, and 86% of hospital charges in US children's hospitals [3].

In a study conducted with children in the literature, 54% of the patients were boys and 46% were girls, the mean age was 8.87 ± 4.6 years, 58.7% had Cerebral Palsy (CP) and Motor Mental Retardation (MMR), 34.9% had tracheostomy, 20.6% used home ventilator because of chronic respiratory failure, 71.4% used home ventilator, nasal cannula or oxygen (O₂) with mask, nasogastric tube, Percutaneous endoscopic gastrostomy (PEG), wheelchair etc. It was also found that the person who primarily cared for children was their mother with a rate of 95.2% [2]. In another study, it was determined that children who were discharged home from the pediatric intensive care unit had a mean age of 85.63 ± 58.40 months, 56.7% were male, and 40% were followed up with a diagnosis of neurological disease [4]. It was also determined that all of the children who were discharged from the intensive care unit had tracheostomy, 96.7% used home-type mechanical ventilators, and 93.3% were fed enterally. It was found that 86.7% of the families applied to the Home Healthcare Services Coordination Center, but only 36.7% received support services and the highest rate of the service received was medical treatment or follow-up by 23.3%. It was found that tracheostomy replacement, tracheostomy care, aspiration, nasogastric/orogastric tube insertion, urinary catheter insertion, exercise, body care etc. were not performed by home care services teams. A total of 93.3% of the families reported that they might face irreversible problems at home in an emergency [4].

It has been emphasized that there is a need for descriptive studies to develop home healthcare services for children who have special health needs, meet the health needs of children at home, direct policies in home health services, meet the physical, social, spiritual, economic and environmental needs of families, set standards in practice and guide social services, home healthcare for children [2,5]. For this reason, the present study can contribute to the identification of needs and information needs about children who have special needs and their families who are in need of home healthcare [5], to intervention studies to be conducted to reduce the care burden of families [6,7], and to the education, counseling and care roles of home healthcare nurses [8]. The purpose of the present study was to examine the descriptive data regarding the children, their families, and living conditions in the records of home healthcare services provided for children between 01.04.2020 and 01.04.2021 at a children's university hospital.

Methods

Figure 1. Flow Diagram



The population of the study consisted of the 342 files registered at the Health Sciences University (SBU) Izmir Dr. Behçet Uz Pediatric Diseases and Surgery Training and Research Hospital Home Healthcare Services between 01.04.2020 - 01.04.2021. Among these 342 files, a total of 172 files were excluded from the study because 66 of the patients had died, 49 of them had turned 18, 18 had changed residence, 7 had recovered, and 32 had incomplete files. As a result of the Power Analysis, the population size for the sample size was calculated as 342 in this study with a 5% margin of error, a population rate of 50%, and a total sample size of 152 children with 90% power. The sample consisted of the files of 170 living and followed-up children between the ages of 0-18 who were registered at (SBU) Izmir Dr. Behçet Uz Pediatric Diseases and Surgery Training and Research Hospital Home Healthcare Services between 01.04.2020 - 01.04.2021. A total of 170 files that met the criteria were included in the study (Figure 1).

The data were collected through the data registration form created by the researchers in accordance with the contents of the files kept for the patients. Patients' gender, average age, diagnosis types, medications/medical device/orthosis/prosthesis status of patients, income status of patients,

social security status of patients, need for care and support of patients, feeding routes of patients (oral, nasogastric tube and percutaneous enteral gastrostomy), whether or not patients need physical therapy, whether or not the patients use a home-type mechanical ventilator, the number of patient visits, the people who care for the patients, the degree of relation of the primary caregiver, the personal daily needs/habits of the patients/chronic diseases status, physical examination and other relevant information held on behalf of the patient, including factors such as their conditions, psychological status evaluations, pain/pressure ulcer/specific healthcare needs, conditions, identification of home healthcare needs are included in this form. To conduct the study, an application was made for the preliminary permission of (SBU) Izmir Dr. Behçet Uz Pediatric Diseases and Surgery Training and Research Hospital Clinical Research Ethics Committee on 16.06.2021, and Clinical Study Ethics Committee Approval was received from the Clinical Study Ethics Committee on 08.07.2021 with the protocol number 591 and decision number 2021/12-09. Informed consent was obtained from the participants for the study. The data obtained by scanning the records were used with the SPSS 25.0 package program (Statistical Package for Social Sciences). The percentage, mean, frequency, minimum-maximum value, and mean values were used for descriptive analysis. The Pearson Chi-Square Tests were used to compare the suitable groups and $p < 0.05$ was considered significant.

Results

In this part, the data in the files of the children who received service from the home care unit included in the study, the sociodemographic characteristics of the children, the diagnosis of their diseases, their dependency status in daily living activities, their home conditions, reasons for applying to the unit, and distribution in terms of device and care material requirements are included.

When the files of the children who received service from the home healthcare unit were examined, it was found that 54.7% of them were male, 24.7% were between the ages of 0-4, 27% were between 5-9, 34.1% were between 10-14, and 14.2% were between 15 and over. Also, 97.6% of children received primary care from their mothers, and 61.2% had social security institution (SSI). When the family income information was reviewed, it was found that 69.4% of the families of the children had a regular monthly income (Table 1).

Table 1. Distribution of sociodemographic characteristics of children receiving home health services

Sociodemographic Characteristics	n	%
Gender		
Female	77	45.3
Male	93	54.7
Age group		
0-4 years of age	42	24.7
5-9 years of age	46	27.0
10-14 years of age	58	34.1
15 years of age and above	24	14.2
Caregiver		
Mother	166	97.6
Grandmother	1	0.6
GDCS	3	1.8
Social Security		
SSI	104	61.2
Other (mostly green card etc.)	66	38.8
Income Status		
Regular Monthly Income	118	69.4
Other Incomes (social aids, unemployment payment etc.)	52	30.6
Total	170	100.0

Social Security Institution: SSI; General Directorate of Child Services: GDCS

A total of 51.8% of the children who received service in the home healthcare unit had a neurological disease. When the types of drugs used by children were examined, it was found that 57.3% used antiepileptic drugs and 16.8% used muscle relaxants. However, 11.1% of them have allergies. It was found that 58.8% of them were fully dependent and 35.3% were semi-dependent in terms of daily life activities and 27.1% of the children who received service in the Home Healthcare Unit used mechanical ventilators, 48.7% were fed orally, 27.7% were fed through nasogastric route, and 23.6% were fed through PEG (Table 2).

Table 2. Distribution of disease diagnosis and treatment characteristics of children receiving home health services

	n	%
Disease diagnoses		
Neurologic	88	51.8
Genetic	40	24.0
Muscle	16	9.9
Cardiac	8	5.0
Respiratory	8	5.0
Metabolic	7	4.3
Allergy Status		
Yes	19	11.1
No	151	88.9
Allergy Types		
Unknown	8	42.1
Known (drug allergy food allergy)	11	57.9
Activate Dependency Status		
Independent	10	5.9

Half-independent	60	35.3
Dependent	100	58.8
Mechanic Ventilator Status		
Yes	46	27.1
No	123	72.3
Intra-Hood Follow-up	1	0.6
Enteral Nutrition Status		
Oral	83	48.7
Nasogastric	47	27.7
PEG	40	23.6
Total	170	100.0
Drugs Used		
Antiepileptic	129	57.3
Myorelaxant	38	16.8
Antihypertension	8	5.8
Digestive System	13	2.3
Metabolic	12	5.4
Other (Vitamin, Anticoagulant etc.)	25	12.4
Total	225	100.0

Percutaneous endoscopic gastrostomy: PEG

When the types of residences in which the children who received service from the home healthcare unit lived were evaluated, it was seen that 72.4% of them lived in apartments, 64.8% of them lived in the living room of the house, and 35.2% of them lived in their rooms. It was also determined that 32.9% of the children's houses are heated with stoves and 38.8% with central heating, and 57.1% of them used Alaturka toilet in their homes. Also, 92.4% of the children whose files were examined had good hygiene in their homes and 98.8% had good lighting (Table 3).

Table 3. Home conditions of children receiving home health care

	n	%
House Type		
Apartment	123	72.4
Detached House	47	27.6
Room of child		
Living room	110	64.8
Own room	60	35.2
Heating of House		
Stove	56	32.9
Heating System Natural Gas	66	38.8
Air Conditioner	36	21.2
Other (Electric heater, Geothermal Stove, Air Conditioner, Unknown)	12	7.1
Toilet Type		
Alaturka toilet	97	57.1
European-style	62	36.4
Alaturka toilet and European-style	11	6.5
Home Hygiene		
Poor	4	2.3
Moderate	9	5.3
Good	157	92.4
Lighting		
Poor	1	0.6
Moderate	1	0.6
Good	168	98.8
Total	170	100.0

It was found that 19.5% of the children who received service from the home care unit applied to the unit for transfer, 15.9% for a disability health report, and 15.3% for home healthcare services. It was also found that 77.7% of those who received service did not use any assistive device and 11.2% used a wheelchair (Table 4). Activity device: Foot table, battery-operated wheelchair, hearing aid, special shoes, abutment, sphygmomanometer, nutrition probe, etc.

Table 4. Reasons for application of children receiving home care services and their use of assistive devices

Admission Reason	n	%
Transfer	33	19.5
Disabled Health Report	27	15.9
Home Health Services	26	15.3
Renewal of Report	18	10.6
Other	66	38.7
Activity Devices Used by Children		
Non	132	77.7
Wheelchair	19	11.2
Oxygen Tube	5	3
Baby food bag	3	1.8
Activity device	11	6.3
Total	170	100.0

It was found that 4.2% of the children who were included in the study had pressure status and 37.6% used aspiration devices, 21.2% had gastrostomy, 13.5% had an air mattress, and 11.2% had a nebulizer device, and 37.1% needed Oxygen (O₂) support (Table 5).

Table 5. Device and care equipment requirements for children receiving home health care

	n	%
Pressure Status		
Yes	7	4.2
No	163	95.8
Aspiration Device		
Yes	64	37.6
No	106	62.3
Gastrostomy		
Yes	36	21.2
No	134	78.8
Pressure Mattress		
Yes	23	13.5
No	147	86.5
Nebula Device		
Yes	19	11.2
No	151	88.8
The Need for Oxygen (O₂)		
Yes	63	37.1
No	107	62.9
Total	170	100.0

It was determined in the present study that 69.4% (n: 118) of the families had financial income to support themselves, and 31.6% (n:52) of them had poor financial situation. Also, 100% of the individuals who received home healthcare services (n:170) had a social security. Most of the participants 61.1% (n:104) had social security institution, 38.8% (n:66) of them had other social security types (mostly green card, etc.). A statistically significant difference was found between income level and social security status ($X^2= 47.542$ $p^*=0.001$, $df=1$) (Table 6).

Table 6. The comparison of the social security status of children receiving home healthcare services according to family income status

		Social Security Status		Total	Pearson Chi-Square Test	
		Social Security Institution	Other		X ²	df
Income Status	Monthly Income	52(%44.06)	66(%55.96)	118(%69.41)	df	1
	Other Incomes	52(%100)	0	52(%30.59)	p*	p*=0.001
Total		104 (%61.17)	66 (%38.83)	170(%100)		

* Pearson's chi-squared test

Discussion

The purpose of the present study was to examine the descriptive data regarding the children, their families, and living conditions in the records of home healthcare services provided for children between 01.04.2020 and 01.04.2021 at a children's university hospital. It was determined in the study that the age groups were mostly between the ages of 0-9, the mothers in the caring role generally had public social security and regular monthly income, the majority of them lived in apartments and the living rooms, mostly benefited from transport and reporting services, neurological and genetic diseases, antiepileptic and muscle relaxant drugs were used by the majority, Commonly known allergy types in children depend on antibiotics and foods, most of them were dependent and were fed through nasogastric and PEG route, most of them needed O₂ and used aspirators.

It was noteworthy that males constituted the majority in the study. It was found in another study that boys constituted the majority [5], and in another study, girls constituted the majority [9]. It was considered that this might be caused by the regional differences in which the studies were conducted. In Turkey, there is a need for an evaluation of gender and studies explaining the reason for this. In the present study, it was found that almost all children 97.6% were cared for by their mothers. Many previous studies report that the primary responsibility for patient care at home is the mother [4,5,10]. This may be because all mothers are not working, and in traditional terms, women are seen as a priority in care roles. In the study, the primary diagnoses of children were found to be generally neurological and genetic diseases. In a study, it was found that 84% were diagnosed with neuromuscular and 41% with other congenital and genetic disorders [9]. The high detection of neurological and genetic diseases may be caused by kin marriages and perinatal reasons. This shows the importance of early diagnosis services in the public healthcare approach [2].

In the present study, it was also found that children who received home care services mostly used antiepileptic and muscle relaxants. It is necessary to pay attention to the regular intake of these drugs, especially antiepileptic drugs, to avoid children from facing unexpected situations, and healthcare professionals in the provision of home care services should explain this well to the caregivers of children. In the present study, 104 of the 170 children 61.1% benefited from social security institution services through their families. It was found in a study that was conducted in Korea that 64 of the 74 children 85.6% were covered by government insurance. [10]. This difference may be because of the provision of healthcare services and social security systems of countries. In the present study, it was found that the families of more than one out of every four children (30.6%) did not have any incomes (Table 1). Under these circumstances, it is necessary to inform families about social rights and support mechanism and to guide them to the necessary public and private resources. A total of 11.1% were found to have allergy status in the study. It can

be caused by allergies in children. In this case, home healthcare nurse families should be given awareness training on drug allergy and intervention training [11]. In the study, it was remarkable that more than half of the children, 94.1%, were dependent in activities of daily living. For this reason, most children need a family member or nurse who cares for their personal needs such as feeding and going to the toilet [8,12].

In the present study, 27.7% of the children were fed through the nasogastric route and 23.6% of them were fed through PEG. In another study, it was found that 38.1% used PEG and 25.4% nasogastric tubes [2]. This may be because of the diagnoses of children and the natural course of the disease. Since the child is connected to a PEG/ and is fed enterally, the home care nurse should inform the family about the disease, the family must be supported socially, training must be provided to use PEG and repeated at regular intervals, the self-efficacy of the family must be increased, and the family must be supported psychologically [13]. Also, 72.4% of the families stayed in the apartment and 64.8% of the children stayed in the living rooms. In the literature, it was determined that families choose housing by considering the needs of their children [14]. This shows that it is necessary to conduct studies on the social determinants of health and quality of life in families. In the study, it was determined that the majority of the applications were made for 19.5% transplants and 15.9% for report renewals. This may be because of the child's medical diagnosis and urgent needs. In a study, it was reported that the technology-based video program met the needs of families, increased satisfaction, facilitated communication between the family and the hospital, and managed patients more effectively [9], for this reason, there is a need for experimental technological-based studies in home healthcare services. It was found that 37.1% of the children needed O₂ support and 37.6% of them used aspirator devices. This may be because of the child's medical diagnosis. The home care nurse should organize training for the child's emergency needs and symptom management to increase the family's quality of life [4].

In the present study, it is important that a significant difference was detected between the income of the family and the social security status ($X^2=47,542$ $p*=0,001$, $df=1$). In a previous study, it was found that 87.3% of the families had social security from SGK, 3.9% of them had Green Card, and 8.8% of them did not have social security [15]. This may be because as the income level increases, the status of having social security is affected positively [16]. There is a need for future studies to investigate the relationship between income status and social security status.

Limitations

There were some limitations in the present study. The study was conducted in a single center, it had a retrospective design, the number of patients was low, the results of the study included only the individuals who participated in the study, the contents of the forms applied as standard in the home healthcare services of the Ministry of Health of the Republic of Turkey were scanned, there was no information other than that in the scanned forms, and the reliability of the information was based on the accuracy of the authorities who filled these forms were the limitations of the study.

Conclusion

Factors such as the majority of patients registered in home health care services were cared by their mothers, high dependency rates in daily life activities, development of pressure status in some of them, need for dependency on a medical device, change in the suitability of home conditions for care show that patients had varying medical, psychological, and social needs. For this reason, it would be useful to focus on pediatric activities in home health care services, open a certificate program for those who provide these services, and develop joint projects for families with the Ministry of Family and Social Services and the Ministry of Health. The exact number of children who are in need of home health care services in Turkey is not known. For this reason, a national action plan must be prepared to improve home health care services.

Conflict of Interest: The authors declared no conflict of interest regarding this article.

	Author	Contributions Author Initials
SCD	Study Conception and Design	AUT, TÇ, ÖK
AD	Acquisition of Data	AUT, ÖK
AID	Analysis and Interpretation of Data	AUT, TÇ, ÖK
DM	Drafting of Manuscript	AUT, TÇ, ÖK
CR	Critical Revision	AUT, TÇ, ÖK

Financial support: No financial support was received from any institution or person for our study.

Prior Publication: This Research was conducted online on November 9-12, 2021 at the 3. It was presented as a verbal statement at the International Congress on Home Care and was presented at the 2nd congress. He has received the like award. but it has not been published in journal.

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