ORİJİNAL ARAŞTIRMA ORIGINAL RESEARCH

Prevalence of Nuclear and Extended Family with at Least One Disable Individual in Turkey

Türkiye'de En Az Bir Engellinin Olduğu Çekirdek ve Geniş Aile Prevalansı

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ABSTRACT Objective: Depending on the changing definition of disability and its classification systems in the world, the data collection criteria regarding the profile of those with disabilities in Turkey have been exposed to transformation as well. There are very few family based studies conducted with samples representing Turkey, yet there is a great need for such a scientific data. This study aimed to determine the prevalence of disabled individuals with respect to their disability types in Turkey. **Material and Methods:** In this study, Lincoln-Petersen, Chapman and Bailey Capture-Recapture methods were applied to estimate the population size of nuclear and extended families with at least one disabled individual and disability prevalence in Turkey. Uludag University students were regarded as sample population to represent Turkey because the students came from all regions of Turkey. To generalize the study, the students were asked to provide information about their families. **Results:** Out of the 38.258 students, the number of nuclear family with at least one disabled individual is estimated with Bailey method is 637, with Chapman method is 649 and with Lincoln-Petersen is 833. While the number of extended family with at least one disable individual s estimated with Bailey method is 4.608, with Chapman method is 4.625 and with Lincoln-Petersen is 4.898. **Conclusion:** When the role and importance of family in Turkish society is considered, education of people with disabilities, rehabilitation, social security status, economic living conditions and the socio-cultural living conditions, these needs can be primarily addressed by the means of family base system. In our findings the prevalence of nuclear and extended family with at least one disabled person in Turkey is estimated to be ranging from 1.67% to 2.18% and 12.04% to 12.80% respectively.

Keywords: Capture-recapture; disability prevalence; nuclear family; extended family

ÖZET Amaç: Dünya'daki engelli tanımında ve sınıflama sistemlerindeki değişimlere bağlı olarak Türkiye'deki engelli profili ve veri toplama kriteri de değişime maruz kalmıştır. Türkiye'yi temsil eden örneklemlerle yapılan aile temelli çalışmaların sayısı oldukça düşük olmasına rağmen bu konuyla ilgili bilimsel veriye çok ihtiyaç duyulmaktadır. Bu çalışmada engelli bireylerin Türkiye'de engellilik türlerine göre prevalansının belirlenmesi amaçlanmıştır. **Gereç ve Yöntemler:** Bu çalışmada Türkiye'deki en az bir engelli birey bulunan çekirdek ve geniş aile anakütlesini tahmin etmek için Lincoln–Petersen, Chapman, and Bailey Yakalama-Tekrar yakalama yöntemleri uygulanmıştır. Uludağ Üniversitesi öğrencileri Türkiye'nin tüm bölgelerinden geldiği için Türkiye'yi temsil eden örneklem olarak alınmıştır. Çalışmayı genelleştirmek için öğrencilerden aileleri hakkında bilgi verilmesi istenmiştir. **Bulgular:** 38258 öğrenciden en az bir engelli birey bulunan çekirdek aile sayısı Bailey yöntemi ile 637, Chapman yöntemi ile 649, Lincoln-Peterson yöntemi ile 833 olarak tahmin edilmiştir. En az bir engelli birey bulunan geniş aile sayısı Bailey yöntemi ile 4608, Chapman yöntemi ile 4625, Lincoln-Peterson 4898 olarak tahmin edilmiştir. **Sonuç:** Ailenin Türk toplumundaki önemi ve rolü, engelli insanların eğitimi, rehabilitasyon, sosyal güvenlik durumu, ekonomik yaşam koşulları ve sosyo-kültürel yaşam koşulları göz önünde bulundurulduğunda, bu ihtiyaçlar öncelikle aile tabanı sistemi aracılığıyla ele alınabilir. Türkiye'deki en az bir engelli birey bulunan çekirdek ve geniş aile prevalansının sırasıyla %1.67-%2.18 ve %12.04-%12.80 aralıklarında değiştiği tahmin edilmiştir.

Anahtar Kelimeler: Yakalama-tekrar yakalama; engelli prevalansı; çekirdek aile; geniş aile

Disability has often been defined as a loss of physical, mental, psychological or social capabilities due to a disease or accident, and this loss of such capabilities limits a person's activities.[1,2]

Disability groups include visually impaired (blindness, partially blindness impairments), hearing impaired (deafness, partially deafness impairments), language and speech impairment (language and speech difficulties) orthopedic impairment (mobility and physical impairments), mentally retarded children, and recently hyperactive and autistic children.

Data collection criteria related to the disability profile in Turkey also show transformation related to different disability groups and classification systems in the world. Disabled and Elderly Services Directorate General in Turkey prepared questions related to disability considering the disability questions set for research on disabled individuals proposed by the Washington Group on the development of the united nations. At the same time, such question sets are developed in accordance with the disability health and International Classification Functioning (ICF) proposed by the World Health Organization.

Life standards of the disabled population and the quality of the services provided for these individuals play an important role in such indicators of countries as health care, education, social security, employment, environment, transportation, housing and economic development. In recent years, policies concerning disabled individuals have improved on an international basis. For the purpose of monitoring and evaluating these policies, the collection of such statistics of disabled individuals has gained importance.

Population census is one of the data sources regarding disabled individuals, and the general population census conducted in 1985 and 2000 provided a great deal of information about the number of disabled individuals in Turkey.[3] However, due to the changing population of the country and other specific conditions, there is a need for more updated information about the proportion of disabled individuals to evaluate the consequences of some policies put into effect in such fields as education and health to prevent disability. For this reason, the information provided by the population census in 1985 and 2000 is considered insufficient.[4]

While 'Turkey Disability Survey 2002' conducted by Turkish Statistical Institute is the last study carried out to estimate the rate, type and number of disabled individuals in Turkey. The data collected in the study showed that of the whole population, 1.25% was found to have an orthopedic disability, 0.60% visual impairment, 0.37% hearing impairment and 0.48% mental disability, which all constituted 2.58% of the population.[5]

It is difficult to estimate the proportion of disabled individuals in a population via a with population census. As part of the study, the 2011 Population and Housing Survey was a study conducted to estimate the distribution of disabled individuals on city basis in Turkey. In order to collect the research data that cannot be obtained with the Address-Based Population Registration System (ABPRS), the study was conducted with the sampling method between 3rd October and 31st December in 2011. Together with the new approach to the classification and definition of disability, disability in the Population and Housing Survey focuses on limitations in function rather than on medical approach (organ loss, functional disorders). However, this study is not one that just focuses on disabled individuals.

When the number of disabled individuals in Turkey was considered, there are differences in the data between institutions. National Disability Database established in the development of Head of Disabled Management provides data about disabled people that received 'disabled health board report' and about any other disabled people registered. According to the record of National Disability Database in 2013, the number of disabled individuals was 1.559.222, while in the survey conducted by Turkish Statistical Institute in 2002, the number of individuals with disability was 8.431.937.[5,6] This number shows that many disabled individuals are not covered in their database, or they are not aware

of it. Therefore, apart from the population and housing census conducted in 2011, there is no other official study conducted recently to estimate the prevalence of disabled individuals in Turkey.

It is very difficult to determine the rate of individuals with special needs in the population. There is no reliable statistics showing the percentage of the total population of various disability groups in Turkey. However, the prevalence of disability in different societies shows similarities, and this prevalence is very important in determining education and health policies in Turkey. In many countries, including Turkey, due to the lack of statistical information about disability, the World Health Organization (WHO) estimates are used.[5] In developed countries with registration systems, the information about disabled individuals is obtained from the records of the organizations. Surveys conducted at regular intervals allow compiling the records which do not exist within the organization.

Apart from population census, counting the number of disabled people in Turkey is too difficult because of time constraints, cost, and other similar factors. For that reason, it can be estimated with different methods. One of the statistical methods we come across used to estimate the disabled population size is the "capture-recapture" (CRC) method. CRC methods are applied to estimate the main population size when the number of units in a population is unknown.[7]

While working with disabled individuals, getting the qualitative and quantitative list is very important in determining related policies. There are very few family based studies conducted with samples representing Turkey, yet there is a great need for such a scientific data. This study aimed to determine the prevalence of disabled individuals with respect to their disability types in Turkey. Therefore, this study was conducted to overcome the missing data and information which resulted from lack of such family-themed research representing the general population of Turkey. Review of the related literature revealed that there is no census or estimation regarding the family base of (nuclear or extended) with at least one disabled individual in terms of five groups of disability (orthopedic impairment, visual impairment, hearing impairment, speech and language impairment, and mental impairment) found in Turkey to determine their population size. For this purpose, two source CRC methods were applied to estimate the population size of nuclear and extended families with at least one disabled individual in terms of the five types of disability (orthopedic disability, visual impairment, hearing impairment, speech and language disorder, and mental disability) in Turkey.

We used the study by Turkey Disability Research as a guideline. However, this study was last conducted in 2002, and the importance of the family structure in Turkish society and lack of such family base research on determining the prevalence of disabled individuals encouraged us to conduct the this study.

MATERIAL AND METHODS

In our study, to estimate the prevalence of nuclear and extended families with at least one disabled individual, we used three methods: Lincoln-Petersen, Chapman, and Bailey among the most commonly used two source capture recapture methods. The results of the study provided various insights for Turkey. The Lincoln-Petersen (LP) method is applied in cases where the population is unchanged during the two sampling periods; the units have an equal chance of capturing and appearing in each of the samples.[8] Lincoln-Petersen method is bias when the number elements recaptured in the second sample is small and undefined when the number of elements recaptured in the second sample is zero. Chapman modified the Lincoln-Petersen method to overcome the error and bias in estimating the population size.[9] When the number elements recaptured in the second sample is big enough (greater than 20) Lincoln-Petersen method gives unbias and better estimation of the population size but when it's small it gives a bias and erroneous estimation of the population. Bailey method was modified to avoid the bias and erroneous estimation of the Lincoln-Petersen method.[10] Uludag University students were regarded as sam-

ple population to represent Turkey, because the students came from all regions of Turkey. To generalize the study, the students were asked to provide information about their families.

RESEARCH SAMPLE

The number of students studying in the Gorukle Campus of Uludağ University was 38.258, and the rate of disability in Turkey identified from previous studies was 0.026.[5] Taking these data as a reference, the sample size was calculated as n=1000 with the significance level of α=0.05 and the estimated sensitivity of d=0.01. Both for capture and recapture, the first and second samples were taken as n=1000.

DATA COLLECTION

The research data were obtained using the survey technique. In the questionnaire, the participants were asked regarding whether there is at least one of their nuclear family members (mother, father, sister or brother) or of their extended family members (mother, father, sister or brother, grandmothers, grandfathers, uncles, aunts and cousins) had any disability as well as to provide information about their disability types, ages, gender, city of accommodation, and being dead or alive. In the study, the nuclear family included the participant himself or herself, his or her father and mother, and his or her sister(s) or brother(s), while the extended family included all the family-based relatives mentioned above.

In the study, disability was categorized in five groups: orthopedic disability, visual impairment, hearing impairment, speech and language disorders, and mental disability.

DATA ANALYSIS

The basic assumptions for the application of the two-source CRC method were as follows: the population was closed, that is, no new individual appeared and no existing individual disappeared during the study period; the presence of an individual in the second sample was not influenced by the presence of the same individual in the first sample (assumption of independent data sources); each individual had the equal chance of being in each sample; and the sampled on both occasions could be identified and matched.[7,11] Taking these assumptions into account, the study was conducted in Gorukle Campus of Uludag University in the Fall Semester of the academic year of 2015 - 2016.

The questionnaire prepared in line with the objectives of the study was applied to the students studying at Uludag University Gorukle Campus. The Ethics Committee of Uludag University (Ethics Committee No. 2015-13/5) was asked for permission to apply the survey. The study was based on voluntary participation, and during the data collections of both samples (capture and recapture), the same data collectors were sent to the same destinations. The main three bus stops and metro station of the campus were decided as the destinations of the survey. The capture and recapture processes lasted two weeks (excluding the weekends) with a three-week interval between the two processes.

RESULTS

Out of the 2000 questionnaires applied, 1953 of them were found appropriate for the evaluation. The responses of these 1953 participants (female: 1206. 62%; male: 746. 38%) revealed that the numbers of families with at least one disabled person were 528 for the extended family and 97 for the nuclear family.

During the data collection process, the distribution of disability groups was as follows: the number of orthopedic disability was 372 (47%); visual impairment was 122 (16%); hearing impairment was 108 (14%); speech and language disorder was 44 (6%); and mental impairment was 137 (17%). Table 1 presents frequencies with respect to nuclear and extended families for the first sample, the second sample and both samples.

Table 2 and Table 3 presents the prevalence, standard error and the proportion of overall number of families with at least one disabled person in nuclear and extended families, orthopedic disability, visual impairment, hearing impairment, speech and language disorder and mental impairment as estimated by the Lincoln – Petersen (LP), Chapman (C) and Bailey (B) methods.

TABLE 1: Frequencies of specified nuclear and extended families with disabled individuals.				
Family Type	Disability Type	Number of disabled individuals in the first sample	Number of disabled individuals in the second sample	Number of disabled individuals in both samples
Nuclear Family	Orthopedic	26	26	1
	Visual	7	7	0
	Hearing	12	7	1
	Speech and Language	1	3	0
	Mental	5	9	1
	Overall	50	50	3
Extended Family	Orthopedic	144	137	7
	Visual	41	46	2
	Hearing	54	46	5
	Speech and Language	17	24	1
	Mental	49	81	2
	Overall	256	287	15

The estimated prevalence of families with at least one disabled person in Turkey based on disability groups and overall was obtained at the same time by proportional estimated population size of nuclear and extended families with the population size of the study area 38258.

According to the result of our study, the prevalence of nuclear families with at least one disabled person in Turkey was estimated to range from 1.67% to 2.18%.

In terms of the disability groups, the prevalence of nuclear families with at least one disabled individual for orthopedic disability was estimated to range from 0.92% to 1.77%, for visual impairment to range from 0.15% to 0.16%, for hearing impairment to range from 0.13% to 0.22%, for speech and language disability to range from 0.01% to 0.02% and for mental impairment to range from 0.07% to 0.12%.

The results of the study also revealed that the prevalence of extended families with at least one disabled person in Turkey was estimated to range between 12.04% and 12.80%.

With respect to the disability groups, the prevalence of extended families with at least one disabled person for orthopedic disability was esti-

mated to range from 6.49% to 7.37%, for visual impairment to range from 1.68% to 2.46%, for hearing impairment to range from 1.11% to 1.30%, for speech and language disorder to range from 0.56% to 1.07% and for mental impairment to range from 3.50% to 5.19%.

DISCUSSION

Conducting a census to get information about a population sometimes becomes difficult due to time constraints, the need for a large budget and other factors. When it is not possible to make the census, sampling methods are applied. Sometimes, it may be necessary to know the number of units with specific features. In such case and similar cases, CRC methods can be applied. Typically, we cannot take a complete census of an entire disabled population, so CRC methods are used to formulate estimates of population size.[9]

In this study, we applied Lincoln – Petersen, Chapman, and Bailey two source CRC methods to estimate the population size of nuclear and extended families with at least one disabled individual and to determine the population size of orthopedic disability, visual impairment, hearing impairment, speech and language disability, and

TABLE 2: Estimated population size and descriptive statistics for nuclear families with at least one disabled person according to disability groups and overall.

Disability Group	Method	Estimated number of nuclear family ($\hat{N}$)	Standard Error	95% CI	Prevalence (%) ($\hat{N}$/38258)
Overall	LP	833.33	452.26	0-1719.76	2.18
	C	649.25	267.99	123.98-1174.52	1.70
	B	637.50	273.69	101.07-1173.93	1.67
Orthopedic	LP	676	650	0-1950.00	1.77
	C	363.5	194.86	0-745.42	0.95
	B	351	195	0-733.20	0.92
Visual	LP	-	-	-	
	C	63.00	39.60	0-140.61	0.16
	B	56.00	37.04	0-128.60	0.15
Hearing	LP	84.00	74.46	0-229.94	0.22
	C	51.00	23.92	4.12-97.88	0.13
	B	48.00	24.00	0.96-95.04	0.13
Speech and Language	LP	-	-	-	
	C	7.00	3.46	4.00-13.79	0.02
	B	4.00	2.45	0-8.80	0.01
Mental	LP	45.00	37.95	0-119.38	0.12
	C	29.00	12.65	4.21-53.79	0.08
	B	25.00	12.91	0-50.30	0.07

LP: Lincoln-Petersen; C: Chapman; B: Bailey; CI: Confidence interval.

TABLE 3: Estimated population size and descriptive statistics of extended families with at least one disabled person according to disability groups and overall.

Disability Group	Method	Estimated number of Extended family ($\hat{N}$)	Standard Error	95% CI	Prevalence (%) ($\hat{N}$/38258)
Overall	LP	4898.13	1194.58	2556.75-7239.52	12.8
	C	4625.00	1055.87	2555.49-6694.51	12.09
	B	4608.00	1086.12	2479.21-6736.79	12.04
Orthopedic	LP	2818.29	1012.11	834.56-4802.02	7.37
	C	2500.25	786.58	958.55-4041.95	6.54
	B	2484.00	803.64	908.86-4059.14	6.49
Visual	LP	943.00	636.04	0-2189.64	2.46
	C	657.00	306.75	55.77-1258.23	1.72
	B	642.33	310.75	33.27-1251.40	1.68
Hearing	LP	496.80	199.81	105.18-888.42	1.3
	C	429.83	143.56	148.46-711.20	1.12
	B	423.00	149.33	130.32-715.68	1.11
Speech and Language	LP	408.00	387.48	0-1167.47	1.07
	C	224.00	117.47	0-454.25	0.59
	B	212.50	117.68	0-443.15	0.56
Mental	LP	1984.50	1357.24	0-4644.70	5.19
	C	1365.67	650.28	91.11-2640.22	3.57
	B	1339.33	657.30	51.02-2627.65	3.5

LP: Lincoln-Petersen; C: Chapman; B: Bailey; CI: Confidence interval.

mental impairment. The close values obtained from three estimation methods increased the accuracy level of the estimates. On the other hand, the reason why we took the students studying at Uludag University Gorukle campus was that the campus admits students from all different regions of Turkey and that the families of the students had the power to represent the entire Turkish population. The study is considered to be important since it tried to determine the prevalence of disability in terms of the family structure. In our study, due to lack of such family-based studies, getting information about extended families representing Turkey in general could be regarded as the strength of the present study in terms of overcoming lack of such information and data.

Considering the importance and role of a family in Turkish society, it could be stated that it is now necessary to take the family as a system in terms of such factors as the education of disabled individuals, their rehabilitation, social security status, economic living conditions and socio-cultural living conditions. According to our findings, approximately 12.8% of the families in the Turkish population are estimated to have at least one disabled individual. The family structures in Turkey show more extended families in the rural areas, while nuclear families are more in urban areas specifically due to the urbanization and migration in recent years. However, the family is still important for individuals and for the society in Turkey. This estimated rate (12.8%) in the 75-million Turkish population is a sign that shows more families are influenced by this situation. At the same time, this value not only shows the problem suffered by people living with disability but also shows the problem that affects their families and communities in psychological, social and economic aspects. Moreover, this situation should help become aware of the negative effects of living with a disability on disabled individuals in terms of health status, education, employment acquisition and social living. Therefore, services to be provided in relation to the family's education, health, social security and employment should obviously be regarded as an indispensable part of the disabled' education, social security and employment.

In developed countries, starting with the diagnosis of a disabled person, the family is considered as part of the process.[10] Several related studies have been conducted in Turkey, and for many years, special services of education and special care is given to people who needed such services have been given only to those with the disability, and these services did not cover the whole family as a system.[12] However, disabled individuals interact first with their family and then with the environment outside. In this process, although the family is the environment where most of the problems occur, families are less considered and kept out of the services offered. Therefore, considering the high number of families affected by disability, it is thought that it will be useful to reach families and to provide them with guidance and counseling services.

The results of our study showed that the prevalence of the nuclear family with at least one disabled individual was approximately 2.18% including 1.5 million people found with disability in the 75-million Turkish population. This value appeared to match the results of the study titled 'Turkey Disability Survey 2002' (2.58%), which was carried out by Turkish Statistical Institute in 2002. This situation indicates that the number of disabled individuals in the past ten years increased in line with the increasing population. The fact that the disability rate did not decrease in years clearly revealed the need for planned policies to be implemented control and prevent the disability status. Therefore, the early intervention and prevention policies taken in Turkey are considered to be insufficient to cope with the problem.

In our study, when the orthopedic, visual, hearing, speech and language, and mental disability groups were examined based on the family type, it showed that the prevalence of the families with an orthopedic disability was the highest in both nuclear and extended family types. This finding appears to match with those obtained in previous studies (Turkey Disability Survey 2002 and population and housing census 2011) carried out by Turkish Statistical Institute. In both nuclear and extended families, the prevalence of orthopedic

disability was the highest, which can be related to the high number of traffic accidents or the impact of terrorist attacks due to the location the country.

When the results of our study were examined, it was seen that the speech or language disability was the least frequent disability type for both family types (nuclear and extended). Also, this value appeared to be matched with those obtained in previous studies (Turkey Disability Survey 2002 and population and housing census 2011) carried out by Turkish Statistical Institute.[5,13]

This study was conducted with the data obtained at Uludag University, which brought some limitations to the study. With the sample size determined in accordance with the research method, the number of disabled individuals captured in the sample was found to be lower than 20 as in the mental disability sub-group. Despite the similar values from the three analysis methods, if the number of recaptured individuals was not big enough (greater than 20), the estimation results of the population size obtained will be baised.[14]

In many countries like America, Canada, Sweden and Ireland, all disabled individuals are recorded in the national database after birth, and all relevant institutes use the database in a coordinated manner. In this way, the health, education, and career development of disabled individuals can easily be provided with the necessary support for lifetime.[15] While the rate of the disabled individuals is estimated to be 2.18% of the population in Turkey, there is no updated database for these individuals. For disabled individuals to make use of such needs as health, education, and employment, the database for disabled individuals could be suggested.

In order to get a deeper knowledge of needs like education, health, career development, and employment of disabled individuals in Turkey, there is a need for research in different environments using different quantitative and qualitative analysis methods. The existence of many nuclear and extended families with disabled individuals in

Turkey and the effects of disability on these families can be examined with various research methods.

CONCLUSION

When the role and importance of family in Turkish society is considered, education of people with disabilities, rehabilitation, social security status, economic living conditions and the sociocultural living conditions, these needs can be primarily addressed by the means of the family base system. In our findings the prevalence of nuclear and extended families with at least one disabled person in Turkey is estimated to be ranging from 1.67% to 2.18% and 12.04% to 12.80% respectively.

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