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Access to Health Services by the Parents of Individuals with Intellectual Disability, According to their Health Literacy Levels

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ABSTRACT

Objective: Health literacy is designated as a "Social Barrier" to accessing health services. The aim of the study was to determine the access status of the parents of mentally disabled individuals to health services according to their health literacy levels.

Methods: The universe of this descriptive study consisted of the parents of individuals with intellectual disability (N:118). The data collection instruments used in the study were the Health Literacy Scale for Turkey-32 and an Access to Health Services Assessment Questionnaire. Ethics Committee permission and approvals were obtained.

Results: A statistically significant difference was found between the caregivers' health literacy levels and their knowledge of how to benefit from health services, their ability to understand the information given to them by health personnel, their ability to correctly communicate their needs, their access to health services and to adequate information, their ability to understand the information gathered and to obtain an appointment from health institutions, their tendency to give up due to the difficulties they faced in procuring an appointment, and their physically being unable to reach health services (p<0.001).

Conclusion: The health literacy levels of many of the participants were limited and inadequate. Those with high levels of health literacy were better able to access health information resources, health facilities and services compared to those with low levels of health literacy.

Keywords: intellectual disability, parent, caregiver, health literacy, access to health services, policy

1. INTRODUCTION

A poor level of health literacy is generally regarded as a strong social barrier to accessing health services (1). Health literacy (HL) refers to an individual's capacity to access health services and fundamental health information, and to process and understand this information in order to use it efficiently. This capability allows an individual to not only access health services but to develop an enhanced competence to maintain the ability to deal with different types of data that will help in the management of a medical condition and increase the individual's future navigation of the health system (2,3).

Health literacy levels (HLL) are indirectly proportional to health care utilization and expenditure. Individuals with HLL's below the basic level are seen to have more prescriptions than those with a basic HLL; these prescriptions usually apply to health services and display a greater frequency but are sometimes unnecessary, thus causing a rise in n health services expenditure (4). It has been reported in many studies that low HLL's can affect or worsen the health outcomes of elderly and disabled individuals due to a decreased utilization of preventive healthcare services, increased difficulty with obtaining medicines and the inability to interpret medicine leaflets and other information (3-5). It is estimated that there are about 978 million individuals with disability in the world today. Approximately 1%-3% of the global population (200 million people) have a disability (6). In Turkey, this rate is 6.9% of the national population (4 million people) (7).

Disadvantaged groups such as individuals with disability and their relatives face the adversities of limited access to health services and they are also affected by an inadequate or limited level of health literacy. For this reason, they run the risk of

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obtaining insufficient and/or inappropriate healthcare (8,9). In recent years, researchers have reported that individuals' health literacy levels hold much more significance for the caregivers of these individuals (10,11).

In a study conducted with disabled adults in the United States in 2013, it was found that the frequency at which individuals with disability accessed facilities to obtain Pap smear tests, mammograms and colorectal cancer scans was lower than it was among non-disabled individuals (12). It was reported in a study by Chinn that the failure of interventions designed to protect and improve the health of individuals with intellectual disability was to a large extent the result of the fact that the health literacy levels of the intellectually disabled and their caregivers were not taken into consideration (13).

Health literacy levels are one of today's most important public health issues (14). The responsibility of identifying the current health literacy levels of individuals with disability and their caregivers, especially the parents of these individuals, providing them with needed information, and acting in line with this information falls upon the shoulders of healthcare professionals. In the light of this knowledge, it is noted that both academics and practitioners refer to inadequate health literacy as the "silent epidemic" that encompasses most of the world population (15). Some of the reasons the present study was conducted with the caregivers of individuals with intellectual disability include the fact that this group represents the most severely disadvantaged group in the population. Individuals in this group are generally unable to manage their own health and inevitably need the assistance of a caregiver and, because of their vulnerability, it will most likely be their parents who will be their primary caregivers and the ones who are in a position to make decisions on their behalf (16,17). Because of this, caregivers need to have a high degree of sensitivity. Targeting and raising the level of health literacy of individuals with disability and their caregivers has been formulated as a political goal in national plans of action (18). Caregivers who provide care to individuals with intellectual disability urgently need to be a part of the conversation surrounding health literacy (14). There is only a limited number of studies looking into the health literacy levels of individuals with disability and their caregivers and the access of this group to healthcare services. The aim of this study is to determine the health literacy levels of the parents of individuals with intellectual disability and their access to health services based on their HL levels.

2. METHODS

2.1. Study Design

The study was conducted with descriptive design.

2.2. Sample

This study was conducted over the period January – May 2018. The universe of the study comprises the parents of individuals with intellectual disability attending a training program at three separate private training and rehabilitation centers (N:280). A sample selection was not made; an attempt was made to reach the entirety of the study universe (n:118). Inclusion criteria for the study were being a primary caregiver to the disabled individuals in the study and consent to participate in the research. Parents who themselves had a disability were excluded from the study. The research question was formulated as: Are there differences between the health literacy (HL) levels of the parents of individuals with intellectual disabilities and their access to health services?

2.3. Measurements

Data collection tools were the Sociodemographic Questionnaire, Access to Health Services Assessment Questionnaire and the Health Literacy Scale for Turkey-32.

Sociodemographic Questionnaire: This questionnaire contains 8 questions on gender, age, health insurance, civil status, education level, income level, employment status, relationship to the individual with intellectual disability. This form was drawn up by the authors in line with the literature (2,3,5,13,14).

Access to Health Services Assessment Questionnaire: This questionnaire, consisting of 10 items, was drawn up by the authors on the basis of a scan of the literature. The questions relate to physical access to health services, information provided about health services, training, understanding materials, being able to communicate one's needs, and being able to organize appointments. The form was drawn up by the authors in line with the literature (1,2,5,9,11-13,15).

Turkish Health Literacy Scale-32: This scale, developed by Okyay and Abacıgil, evaluates the health literacy levels of individuals over the age of 15 or with minimum language literacy. There are 32 questions. The scale is based on a conceptual framework that was developed by the European Health Literacy Consortium Each item is scored on a 4-point scale as: 1=Very easy, 2=Easy, 3=Difficult, and 4=Very difficult. The response "I have no idea" was coded 5. The level of health literacy was assessed in four categories according to the scores obtained: (0-25): inadequate; (>25-33): problematic-limited; (>33-42): adequate; and (>42-50): excellent (19). Cronbach's alpha coefficient for the original questionnaire is 0.92. In this study, Cronbach's alpha was 0.80.

2.4. Data Collection

The participants were informed about the study and their consent was obtained. Data were collected from each participant in an average of 30-45 minutes through face-to-face interviews.

2.5. Data Analysis

The data collected were evaluated using descriptive statistics and chi-square analysis. Komolgornov Smirnov test was used for normal distribution. Statistical analyses were carried out using the statistical software package SPSS Statistics for Windows, version 17. The level of significance was accepted to be 0.005.

2.6. Ethical Considerations

Approvals for the study were obtained from the University Ethics Committee (08.01.2018-3) and the institutions involved. The participants provided their voluntary consent to be a part of the study. Since we would be working with a vulnerable/special needs group, a specialist in Clinical Psychology was asked to review our questions and the necessary adjustments were made. The research conforms to the provisions of the Declaration of Helsinki (20).

3. RESULTS

All of the participants were the caregivers of individuals with intellectual disability; 8.4% were women, 18.6% were men. Their mean age was 42.6±10. Among the participants, 6.9% had no health insurance, 12.8% were divorced/widowed and 67.6% were unemployed. Only 28% were university graduates. A group of 43.1% revealed their income to be less than their expenditure; 27.1% had at least one chronic illness. Of the parents participating in the study, 76.6% were mothers of the disabled individuals, 14.4% were fathers. There were significant differences between the health literacy levels and the variables of age, education, income level, and relationship to the disabled individual ($p<0.005$). Of the participants, 63.3% stated that their access to health services was difficult; 92% said they would like to access health services more easily. The open-ended question, "What are the factors that would made access easier?" was answered by 53.2% of the participants. Of the responders, 31.4% mentioned social services, 9.6% referred to economic factors, 6.9% cited more transportation support, 3.7% pointed to facilitating services for obtaining appointments, and 1.6% stated that eliminating the collection of additional medication costs would make access to health services easier.

In looking at the participants' health literacy levels, it was found that 7.4% had inadequate, 55.9% had limited, 23.9% had adequate and 12.8% had excellent HLLs (Graph 1). The overall mean health literacy score was 32.51 (inadequate; >25-33).

Of the participants, 24.46% said they were unable to meet their needs at the health facilities, 72.34% revealed that they were unable to understand the informative materials that would lead them to health services, and 36.7% said they had physical difficulty in reaching health services. A statistically significant difference was found between health literacy levels and the ability to meet one's needs from health facilities in the city of residence (e.g., hospitals, rehabilitation centers, family health centers, pharmacies) ($x^2=21.51$; $p<0.005$), understanding publications providing information about easily accessible health services (e.g., webpages, brochures, journals) ($x^2=19.10$; $p<0.005$),and having physical difficulty reaching health services ($x^2=26.82$; $p<0.001$) (Table 1).

Table 1. *Access to health services by the parents of individuals with intellectual disability according to their health literacy levels*

Access to Services		Health Literacy Levels							
		Inadequate Health Literacy *n %*		Limited Health Literacy *n %*		Adequate Health Literacy *n %*		Excellent Health Literacy *n %*	
Can you meet your needs from the healthcare facilities (hospitals, rehabilitation centers, family health centers, pharmacies and others)in the city you live in?	Yes (n=142;75.5%)	5	2.7	80	42.6	35	18.6	22	11.8
	No (n=46; 24.4%)	9	4.8	25	13.3	10	5.3	2	1
Total	n=188	14	7.4	105	55.9	45	23.9	24	12.8
Statistics:			x^2 = 21.51			p= 0.001			
Can you understand materials that give you information about accessing health services (webpages, brochures, journals and others)?	Yes (n=52; 27.7%)	1	0.5	23	12.2	18	9.6	10	5.3
	No (n=136; 72.4%)	13	6.9	82	43.6	27	13.3	14	7.4
Total	n=188	14	7.4	105	55.9	45	23,9	24	12.8
Statistics:			x^2 =19.10			p= 0.004			
Do you find it physically hard to get to health services?	Yes (n=119;63.2%)	14	7.4	64	11.7	11	17.5	8	4.3
	No (n=69; 36.7%)	0	0.0	41	21.8	12	6.4	16	8.5
Total	n=188	14	7.4	105	55.9	45	23,9	24	12.8
Statistics:			x^2 =26.82			p= 0.000			

x2= Pearson Chi-Square

Of the participants, 45.2% said they were unable to understand the information health professionals provided (e.g., diagnoses, tests, prescriptions), 64.36% could not understand the materials distributed after information/training was provided, 38.29% could not comprehend the training given, and 19.14% revealed that they could not express their needs accurately. A statistically significant difference was found between health literacy levels and the difficulty experienced in understanding the information provided by health professionals (e.g., diagnosis, tests, prescriptions) (x^2=35.43; $p<0.001$), understanding the materials distributed after information/training was given (x^2=30.65; $p<0.001$), understanding the health training (x^2=33.64; $p<0.001$), the ability to express a complaint or need accurately (x^2=25.19; p=<0.001). The number of individuals with limited and inadequate HLLs who experienced difficulty in accessing HS was greater than those with adequate or excellent health literacy (Table 2). Caregivers with a low level of HL use health services less productively than those with adequate or excellent HL levels.

Additionally, 70.74% of the participants said they had difficulty in obtaining appointments from health facilities, 50.53% said they gave up on trying to make appointments and 69.14% stated that they ended up not getting an appointment because of the long waiting period. There is a statistically significant difference between health literacy levels and having difficulty obtaining an appointment from a health facility (x^2=19.62; $p<0.005$), giving up on getting an appointment due to the difficulty involved (x^2=20.08; $p<0.005$), and not getting an appointment because of the long waiting period (x^2=42.49; $p<0.001$) (Table 3).

Of the participants, 27.65% stated that they could not reach the financial and social resources provided for access to health services. There is a statistically significant difference between health literacy levels and the ability to reach financial and social resources in order to access health services (x^2=14.6; $p<0.005$) (Table 4).

Table 2. *Understanding the Information, Training and Materials and Expressing Needs regarding HS, by Level of Health Literacy*

The Information, Training and Materials and Expressing		Health Literacy Levels							
		Inadequate Health Literacy		Limited Health Literacy		Inadequate Health Literacy		Excellent Health Literacy	
		n	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Do you have difficulty understanding the information (diagnosis, tests, prescriptions and others) healthcare professionals give you?	Yes (n=85; 45.2%)	13	6.9	51	27.2	16	8.6	5	2.7
	No (n=103; 54.7%)	1	0.5	54	28.7	29	15.4	19	10.1
Total	n=188	14	7.4	105	55.9	45	23.9	24	12.8
Statistics:				x^2 = 3 35.4		p= 0.000			
Can you understand the information sheets or materials (short notes, brochures, etc.) given to you after training?	Yes (n=67; 35.63%)	1	0.5	34	18.1	16	8.5	16	8.5
	No (n=121; 64.36%)	13	6.9	71	37.8	29	15.4	8	3.2
Total	n188	14	7.4	105	55.9	45	23.9	24	12.8
Statistics:				x^2= 30.65		p= 0.000			
Can you understand the health training given to you?	Yes (n=116; 61,70%)	0	0.0	69	36.7	28	14.9	19	10.1
	No (n=72; 38.29%)	14	3.2	36	19.2	17	2.1	5	2.7
Total	n=188	14	7.4	105	55.9	45	23.9	24	12.8
Statistics:				x^2= 33.64		p= 0.000			
Can you accurately explain/ask questions about your condition/needs?	Yes (n=152; 80,85%)	5	2.7	88	46.8	37	19.7	22	11.7
	No (n=36; 19.14%)	9	4.8	17	9.0	8	4.2	2	1.0
Total	n=188	14	7.4	105	55.9	45	23.9	24	12.8
Statistics:				x^2 = 25.19		p=0.000			

x2= Pearson Chi-Square

Table 3. *Access to services of parents of individuals with intellectual disability according to their health literacy levels*

Access to Services		Health Literacy Levels: Inadequate Health Literacy *n*	*%*	Limited Health Literacy *n*	*%*	Inadequate Health Literacy *n*	*%*	Excellent Health Literacy *n*	*%*
Do you have difficulty obtaining appointments from healthcare facilities?	Yes (n:133;70.74%)	13	6.9	55	29.3	28	14.9	7	3.8
	No (n=85; 45.21%)	1	0.5	50	26.6	17	9.0	17	9.0
Total	n =188	14	7.4	105	55.9	45	23.9	24	12.8
Statistics:				x^2 = 19.62			p= 0.003		
Do you ever give up on getting an appointment when you have difficulty?	Yes (n=95; 50.53%)	13	6.9	51	27.1	24	12.8	7	3.8
	No (n=93; 49.46%)	1	0.5	54	28.7	21	11.2	17	9.0
Total	n=188	14	7.4	105	55.9	45	23.9	24	12.8
Statistics:				x^2 = 20.08			p= 0.003		
Have you ever been unable to get an appointment because of the long waiting period?	Yes (n=130;69.14%)	14	7.4	69	36.8	36	19.3	11	11.9
	No (n=58; 30.85%)	0	0.0	36	19.1	9	4.8	13	6.9
Total	n= 188	14	7.4	105	55.9	45	23.9	24	12.8
Statistics:				x^2 = 42.49			p =0.000		

x2= Pearson Chi-Square

Table 4. *Access to health and social support services according to the health literacy levels of parents of individuals with intellectual disability*

Access to Health and Social Support Services		Health Literacy Levels: Inadequate Health Literacy *n*	*%*	Limited Health Literacy *n*	*%*	Inadequate Health Literacy *n*	*%*	Excellent Health Literacy *n*	*%*
Accessing financial and social resources in order to access health services	Yes (n=136;72.34%)	13	5.9	76	40.4	34	18.0	13	6.9
	No (n=52;27.65%)	1	1.5	29	15.4	11	5.9	11	5.9
Total	n=188	14	7.4	105	55.8	45	23.9	24	12.8
Statistics:				x^2 = 14.68			p = 0.023		

x2= Pearson Chi-Square

4.DISCUSSION

According to the Turkish health literacy survey, the average score of the Turkish population on the general health literacy index is 30.4. A group of 64.6% of the population has an inadequate or problematic level of health literacy (21). Okyay and Abacıgil have found the general health literacy score of the Turkish population to be 29.5. The health literacy levels of 69.4% of their study participants were "inadequate – problematic." This is a very high level, and the researchers reported that most of the population exhibited "inadequate-limited" levels of health literacy. In our study, the mean general health literacy score of the participants was 32.51; 63.3% showed "inadequate – problematic" levels of health literacy. In the United States, only one out of every 10 adults are health-literate. Among adults in the USA, 12% are reported to have adequate health literacy levels (HLL), while 53% and 22% have moderate and basic health literacy, respectively, and 24% have sub-optimal basic health literacy (22). The likelihood of living with suboptimal health conditions, having less access to the healthcare system and inadequately benefiting from health services is greater among individuals with low levels of health literacy (1).It was promising to find that the individuals in this study sample had similar or even better HLLs compared to individuals in the general population. At the same time, the percentage of individuals with “inadequate-problematic” literacy levels is similar to what is reported in other studies. Although HL scores appear to be a little better than in the general population, the mean still represents an inadequate (>25-33) level of health literacy (8). The reason the scores of the study participants were not lower/less than those of the general population might have stemmed from the fact that these individuals had long years of experience in caring for the individuals they supervised. There is a study that supports this belief. Murphy, et al. assert in their research that the health literacy scores of caregivers living with individuals who are constantly or frequently being treated may increase over time (23). We also think that the rehabilitation reports used in the Children’s Special Needs Report have a positive impact on caregivers. The fact that a large majority of the population and the parents participating in this study are at an “inadequate-problematic” HLL despite all that is being done makes it evident that the health literacy of primary caregivers, particularly those that care for individuals with disability, as well as persons with diseases such as cervical cancer or chronic diseases such as HIV, needs to be raised in order to improve the health, social and economic outcomes of the individuals they care for (24,25).

Parents’ capacity to serve as advocates must be enhanced so that they can demand the health information and care they seek, ask questions and easily access the healthcare system (23). A statistically significant difference was found between parents’ HL levels and the difficulties they experience in easily accessing health services, understanding informative publications and experiencing trouble in physically accessing health services (Table 1). Again, a statistically significant difference was found between HL levels and the ability to understand health training and educational materials, to understand and ask questions about the sickness/or individual needs, comprehend the information provided by healthcare professionals (e.g., diagnoses, tests, prescriptions) (Table 2). Parallel to these findings, Schmidt et al. have reported that parents with low levels of health literacy do not make productive use of health services. Moreover, a statistically significant difference was found between HL levels and easy access to health services and being able to understand informative publications (26). Robinson C, Graham J et al. report that those with limited/poor HL and inadequate skills in informatics or in seeking out, assessing and using information on health are not able to make effective use of such important resources (27). Health training usually seems quite complex and unsettling to those with limited levels of health literacy (1). In the light of what has been reported by Peters E, Hibbard J, Slovic P, Dieckmann N, who said that if individuals cannot understand health information (e.g., diagnoses, treatments, tests) they will have difficulty in making informed decisions and in participating effectively in the process of health services provision, it can be said that our findings are considerably disquieting (28). On the other hand, when clients understand health information, this increases their capacity to access health services (29). In our study, those with inadequate+limited HL levels did have difficulty with understanding information on diagnoses, tests and prescriptions. Not being able to understand how to use prescribed medications increases the risk of inadvertent dosage repetitions and other errors of medication usage, leading to high medical costs (30). More thought-provoking is that it has been observed that even adult caregivers with excellent health literacy can sometimes make mistakes in medication compliance and administering proper dosages (31). Indeed, Fransen et al. and Loke et al. have shown through their most recent scan of the literature that there is a significant correlation between health literacy and drug compliance (32,33). Those with disabilities have more of a need for health services than others. When the high levels in the usage of health services are considered, it can be seen that those with disabilities are disproportionately affected by the barriers to access created by their disability. It is striking to note that in the case of two persons with the same medical condition, where one has a disability and the other is non-disabled, the individual with disability is likely to use 2-3 times more health services than the non-disabled individual and also has more of a need for these services (9,34). These circumstances and the fact that individuals with disability have both physical and mental health issues and have differences in their medical treatment and cognitive processes indicates that the health literacy levels of caregivers and parents must be raised.

We found in our study a statistically significant difference between parents’ health literacy levels and the difficulties they face in obtaining an appointment from health facilities and in not being able to get an appointment due to a long waiting period (Table 3). In a study by Schultz et al., the authors evaluated the unmet oral health needs of developmentally disabled children (35). The study indicated that one of the factors that had the most influence on the parents’ perception of the need for oral health services was their low levels of health literacy. It was reported that adults with limited health literacy were unable to understand appointment reminders, information sheets, consent forms and lacked the skills to use the healthcare system for access to care. Palumbo has reported that limited health literacy is known to be a social barrier in accessing healthcare services among individuals with HIV. Because of this, limited health literacy has been associated with the poor management of chronic and long-term conditions. Providing the parents of individuals with disability with health education programs is of great importance in improving these circumstances. To manage and avoid adverse circumstances, caregivers and families need to be supported with individual and group programs that should be repeated as necessary.

Our findings suggest that the influence parents with limited levels of health literacy can have on the health of the individuals with disability they care for cannot be ignored. Also, healthcare providers largely neglect the need for health information of parents with low health literacy levels who live with individuals with disability, a circumstance that leads to their inability to obtain effective health services.

Although the variables used in this study are an indication of the access to health services, the fact that the data was collected indirectly constitutes a limitation of the research.

5. CONCLUSIONS

There are significant differences between the participants' HL levels and their ability to access health services. It was concluded that individuals with high levels of health literacy are better able to reach health information resources and access healthcare facilities and services. A large majority of the participants said that their access to health services was difficult and they could not obtain access as much as needed. Our findings on the access to health services of disadvantaged groups have pointed to a strong need for the advocacy of public health nurses and other specialists in this context. Because neither policymakers nor healthcare administrators have adequate awareness about the role HL plays in access to health services, there must be much more of an effort to raise this awareness. In particular, institutional interventions should not be delayed while attempting to achieve effective and prompt access to health services. In this context, we recommend the urgent development of programs that will increase the health literacy of parents of individuals with disability, especially mothers.

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