Parents Health Literacy: A Key Component for Children Rehabilitation with Special Needs

ABSTRACT

Background and Objective: The relationship between parent health literacy and adherence to rehabilitation in children with special needs has not been fully explored. The aim of this study was to determine the association of parent health literacy and other predicted factors with follow-up of occupational therapy (OT) and speech therapy (ST) in children with special needs between 3 and 6 years old, Hamadan city, 2020.

Materials and Methods: In this descriptive-analytical cross-sectional study, 92 parents (64 mothers and 28 fathers), who have children refering to occupational therapy and speech therapy centers, were randomly selected. Data gathering was conducted by demographic and parent health literacy questionnaires, and SPSS software version 16 all data was used to analyze data by independent t-test, ANOVA, Pearson correlation coefficient at a significance level of 0.05.

Results: The mean of father and mother's health literacy were 55.18±7.59 and 61.72 ± 13.56, respectively. A significant difference was observed in parents' health literacy, parent's gender ($p = 0.019$), parent's education level ($p = 0.05$), and father's occupation. Pearson's correlation coefficient analyses showed a significant negative correlation between parental health literacy and father age ($r = -.345$, $p < .01$), maternal age ($r = -.418$, $p < .01$), and parental health literacy positively correlated with the number of OT ($r = .238$, $p < .05$) and ST Sessions ($r = .468$, $p < .01$).

Conclusion: parent's health literacy was inadequate, and level of health literacy was higher in younger and more educated mothers and significantly associated with further follow-up of rehabilitation (occupational therapy and speech therapy). It is necessary to plan educational strategies to increase the level of health literacy in parents who have children with special needs, because of these children are vulnerable population.

Paper Type: Research Article

Keywords: Parents Health Literacy, rehabilitation, children with special needs.

▶ **Citation:** Haghgoo H, Mortazavi Z, Kamyari N, Jafarnejad M, Mortazavi S. Parents Health Literacy: A Key Component for Children Rehabilitation with Special Needs. *Journal of Health Literacy*. Spring 2021; 1(6): 13-19.

Hojjat Allah Haghgoo
Department of occupational therapy, University of Social Welfare and Rehabilitation Science, Tehran, Iran.

Zahra Mortazavi
PhD student of Speech Therapy, Tehran University of Medical Sciences, Tehran, Iran.

Naser Kamyari
Department of Biostatistics, Student Research Committee, School of Public Health, Hamadan University of Medical Sciences, Hamadan, Iran.

Maryam Jafarnejad
Student of Occupational Therapy, Students Research Center, Iran University of Medical Sciences, Hamadan, Iran.

Saideh Sadat Mortazavi
*PhD Candidate, Department of Occupational Therapy, University of Social Welfare and Rehabilitation Sciences, Tehran, Iran. (Corresponding author) S.mortazavi.st@gmail.com

Received: 22 January 2021
Accepted: 12 May 2021
Doi: 10.22038/jhl.2021.55320.1147

Introduction

World Health Organization, reports on disability, indicate that almost 150 million children live with disabilities worldwide (1). Children with special healthcare needs (CSHCN) are defined as "those who have or are at increased risk for a chronic physical, developmental, behavioral,

or emotional condition and who also require health and related services of a type or amount beyond that required by children generally"(McPherson et al., 1998, p. 138) (2). Since, half of the Iranian population had inadequate and marginal health literacy, this was more evident among vulnerable groups (3). Health literacy defined as describing the ability of individuals to locate, interpret, and apply health information to their decisions and health information fluency(4). Health literacy is correlated with general literacy skills. Limited health literacy is more common among adults with low education, poverty-level income, learning or physical disability. Also, shame, low self-esteem, and limited social support are common in adults with limited health literacy skills (5).

Health literacy impacts the ability of parents to direct through health-care systems, receive medical resources, and adequately manage the care of themselves and their children (6). Parent health literacy has been related to adherence the medical treatment. For instance, parent with limited health literacy has been associated with low adherence among children or adolescents with asthma, epilepsy, insulin-dependent diabetes, and road traffic injury (6-9). Outcomes for no adherence include increased mortality, morbidity, utilization of healthcare services, and medical costs (10).

Parents, who have children with special needs, face different specific challenges in carrying out their caregiving roles. They experience more difficulty to care their children due to unusually high expectations(2). Measuring the parent's health literacy in children with special needs is essential to avoid the consequences of limited literacy. This study aimed to investigate the health literacy in parents, who have children with especial need, refer to occupational therapy and speech therapy centers, Hamadan (Iran), 2020.

Materials and methods

In this cross-sectional study of descriptive-analytical type, 92 parents (64 mothers and 28 fathers) with children (3-6 years) referring to occupational therapy and speech therapy centers were randomly selected in spring 2020. In all rehabilitation clinics affiliated with Hamadan University of Medical Sciences (five centers), over a period of two months, all individuals who wished to participate in the study were examined. They completed the demographic and parent health literacy questionnaires. Participants were given the following survey instruments: 1) a demographic questionnaire to assess basic patient characteristics about age (mother, father, child), weight, eighth, BMI (child), education, job (parent), Number of OT sessions, Number of ST Sessions, age of first referral OT and ST, diagnosis and referral of child to rehabilitation (pediatrician, Pediatric neurologist, psychiatrist, rehabilitation specialist, others), and source for following up on child health questions. 2) Validated preschool parent`s health literacy measure that consists of 40 questions in five domains: nutrition, psychosocial/development, injury/safety, numeracy skills, and health information (11).

Each component is scaled from 1 to 3, where 1, 2, 3 indicate the wrong answer, I do not know, and correct answer, respectively. The scores of five components are then summed up to yield a total score from 40 to 120; higher scores indicate

better health literacy. To assess the validity of the test content, the questionnaire was sent to a panel of 9 academic members consisting of experts in the fields of psychology and health education. For each item, the Item Content Validity Index (I-CVI) was calculated. For the Sale Content Validity Index (S-CVI), the I-CVI was calculated for each item and then the average I-CVI were calculated across all items.

Polit and Beck noted that I-CVIs of 0.78 or higher and S-CVI/Ave of 0.90 or higher are acceptable content validity (12). The internal consistency of the questionnaire was evaluated by the Cronbach alpha coefficient and item scale correlation.

Reliability was examined through the Face validity and Content Validity, and validity was confirmed by a Cronbach's alpha of 0.65. Parent were included in this study if they: from Iran, refer by a doctor's diagnosis, have children with 3 to 6 years (hearing loss, mental retardation, physical disorder, behavioral disorders, and autism), have literacy, and ability to perform skills related to numerical arithmetic, Lack of stress in the past year (death of first-degree relatives and immigration), confirm parental consent form, and they excluded if they: use sleeping pills or CNS stimulants that cause It disturbs the parents' consciousness. This research was conducted in the spring of 2020, and researcher in five-outpatient rehabilitation clinics affiliated with the Hamadan University of medical science, within 2 months, collected data.

In order to provide descriptive statistics of the studied variables, central inclination index (Mean, Median) and dispersion indices (standard deviation, variance) were calculated. Kolmogorov–Smirnov test was used to evaluate the degree of conformity of variables with normal theoretical distribution. Independent T-Test and one-way ANOVA were used to compare the mean scores of the questionnaire between different groups. The amount of correlations will also be calculated using the Pearson correlation coefficient. All analyzes are performed in SPSS v.16 software at a significance level of 0.05.

Results

In the present study, 92 parents (64 mothers and 28 fathers) participated. The average age of the fathers, mothers, and children were 34.15 ±6.81 , 31.62± 6.47, and 4.5± 1.1 years. The mean child's body mass index was 57.3 ±27.18 (Normal). Also, 53.8% of children referred to rehabilitation centers were boys and 46.2% were girls.

In most cases, father education (49.5%) and mother education (50.5%) were less than diploma. The father's jobs (56.6%) were self-employed and the mother's jobs (68.8%) were employed. In 45.2% of the cases, the referrals were from a pediatrician (Table1).

Table 1: Demographic information about study participants (qualitative variable)

variable		N	percent
sex	girl	43	46.2
	boy	50	53.8
Number child in family	1	41	44.1
	2	41	44.1
	3	10	10.8
	4	4	1.1
Education father	> diploma	46	49.5
	diploma	37	39.8
	University	10	10.8
Education mother	> diploma	47	50.5
	diploma	26	28
	University	20	21.5
job father	self-employed	48	51.6
	worker	36	38.7
	especial	9	9.7
job mother	Employed	64	68.8
	Housekeeper	29	31.2

Income	500-1500	30	32.3
	1500-3000	31	33.3
	>3000	23	24.7
Diagnosis and referral	Pediatrician	42	45.2
	Pediatric neurologist	20	21.5
	Psychologist/ Psychiatrist	13	14
	rehabilitation specialist	9	9.7
	Other	8	8.6
Source of information for parents	book	7	7.5
	family	28	30.1
	internet	4	4.3
	Health center	51	54.8

The mean age of children's first referral to OT were 27.69±14.18 months (two years and three months) and in general the number of sessions referred to OT were 26.88±14.76 (about 27 sessions).

The mean age of children's first referral to ST were 33.50±10.17 (about three years) and in general the number of sessions referred to ST were 19.07±13.01 (about 20 sessions).

The mean of fathers and mother's health literacy was 55.18±7.59 and 61.72 ± 13.56, respectively (Table2).

Table 2: Health literacy level of parents of children referring to speech therapy and occupational therapy

variable	Father(N=28)		Mother(N=64)		P-value
	M	SD	M	SD	
Health literacy level	55.18	7.59	61.72	13.56	0.019
Nutrition	12.14	3.30	13.17	4.43	0.273
Psychosocial/Development	21.5	3.17	23.25	6.72	0.192
numeracy skills	4	1/09	5.08	3.19	0.086
Injury/Safety	6.86	1.67	8.05	1.99	0.007
health information	10.68	2.11	12.17	2.75	0.012

The results of the T-Test analysis showed a significant difference between parents' health literacy (p = 0.019) and the level of mother's health literacy was higher compered with to father.

Also, the results of one-way analysis of variance showed that the level of father's health literacy in different occupational groups is significantly different and the level of health literacy among father with self-employed work is higher than unemployed/ worker and individuals with especial work (F = 2.718, P = 0.071). The results of the independent t-test showed that the level of maternal health literacy in different occupational groups was not significantly different (P = 0.549).

Pearson correlation coefficient was used to examine the correlation between parental health literacy score and other variables including father age, mother age, OT sessions, ST Sessions, age of children's first OT referral and ST referral. The correlations test showed the weak to moderate correlations between health literacy and the considered variables. The level of health literacy, except of speech therapy referral (r = 0.035) and occupational therapy referral (r = -0.057), had a significant relationship with other variables. Speech therapy sessions had the highest correlation (r = 0.468) with health literacy, while speech therapy referrals had the lowest correlation (r = 0.035) with health literacy level (Table3).

Table 3: Pearson correlation between health literacy level and demographic variables

variable	(1)	(2)	(3)	(4)	(5)	(6)	(7)
(1) Father age	1						
(2) mother age	0.936**	1					
(3) Number of occupational therapy sessions	0.063	0.191	1				
(4) Number of speech therapy sessions	0.081	0.180	0.233	1			
(5) Age of first referral to occupational therapy	0.181	0.142	-.408**	0.464**	1		
(6) Age of first referral to speech therapy	0.377**	0.411**	0.054	-0.074	0.656**	1	
(7) Health literacy level	-0.345**	-.418**	0.238*	0.468**	-.057	0.035	1

*: Correlation is significant at the 0.05 level (2-tailed).
**: Correlation is significant at the 0.01 level (2-tailed).

Discussion

In the present study, the mean level of father and mother's health literacy was 59/7 ±18 /55and 61.72 ± 13.56, which indicates limited parental health literacy. According to the present study, the study of Khudabakhshi et al. (2018) showed that the level of health literacy in children's mothers who have special needs (autism, cerebral palsy, and mental retardation) was generally (45 out of 165 points) inadequate. However, autistic children's mothers had relatively higher levels of health literacy than the other two groups (4). Michelle Dey et al. (2015) studied on health literacy in parents who have children with special care needs. They confirmed that the level of health literacy in parents who have children with mental disorders is lower than parents of children with physical disorders (13). Also in the present study, the level of mother's health literacy, in the areas of safety, health information and the total score of health literacy, was significantly higher than the fathers. Some studies also confirm the results of the present study (13, 14). However, there are studies that showed insignificant differences in the level of health literacy between men and women who considered as the parents or caregivers (15, 16). This difference could be due to the similarity of the items in the male employment and female caregivers as well as the children's duties and needs.

In the present study, parents with higher literacy levels also showed higher levels of education.

The results of studies by Dey et al (2015), Bathory et al (2016), Hassan et al(2010), Glick et al (2019), mozafari et al (2018) suggested that a higher level of education usually leads to better health literacy(13, 15, 17-19). In justifying the reason, it can be said that with increasing the level of education, usually the ability of people to understand and reason about what they read increases, and this will have a positive effect on increasing the level of health literacy.

In this study, parents with higher levels of health literacy and their child referred to occupational therapy and speech therapy, in other words; they are more persistent for rehabilitation and follow up treatment. In other studies, including Abrams et al. (2020) on the health literacy among caregivers of patients with asthma, acknowledged that low health literacy will lead to reduce quality of life, worse of the disease, and frequent hospital emergencies (12) Keim-Malpass J et al. (2015) showed that raising the literacy level in mothers of children with special needs leads to improving the level of appropriate health care delivery(20).Failure to pursue essential care is associated with limited health literacy in parents of children with mental disorders or physical disorders(13)

Previous studies have suggested that special needs or disabilities in children are associated with prenatal, intrauterine, and postnatal causes. Samadibeyk et al. (2013) showed that most parents do not have enough information about the disease and its causes (21). While adequate health literacy during pregnancy has a direct impact on the health of mother and child (22). People with adequate health literacy have skills to improve health-messages, read and understand health experts' instructions critically, and search various websites and media (23). Mothers with children with special needs have problems in these areas (24).

Limitation: This research selected the parents who refer to occupational and speech therapy. Future studies could select other clients to refer to rehabilitation (physical therapy, audiology, and technical orthopedic) and compare results with this study. This research used an available sampling procedure, which is the main limitation of this study due to the prevalence of Covid 19, few clients came to the clinic. Future studies could use a stratified random sampling procedure with more sample size.

Practical implications

It is hoped that the findings of this study will assist the practitioners to better understand some reasons for low-rate follow-up of occupational therapy and speech therapy in children with special needs.

Conclusion: The results of this study showed that the health literacy in parents of children with special needs is inadequate. The variables of age, sex, occupation, and parent's education could be the effective parameters that influence the level of health literacy in parents of children with special needs. Therefore, the level of health literacy was higher in younger and more educated mothers. Also, the level of parental health literacy was significantly associated with further follow-up of rehabilitation (occupational therapy and speech therapy). It is necessary that health officials to plan treatment and educational strategies to increase the level of health literacy in parents of children with special needs, because of these children are vulnerable population.

Ethical Considerations: The study protocol was approved by the Ethics Committee of Hamadan University of Medical Sciences (No. IR.UMSHA.REC.1399.124).

Funding: This study was supported by Hamadan University of Medical Sciences (Grant No. 990223976).

Conflict of interest: The authors declared no conflict of interest.

Acknowledgements: We thanks all parents of children with special needs who participated in this study and also appreciate rehabilitation centers for their cooperation

References

1. Chen X, Velez JC, Barbosa C, Pepper M, Gelaye B, Redline S, et al. Evaluation of actigraphy-measured sleep patterns among children with disabilities and associations with caregivers' educational attainment: results from a cross-sectional study. BMJ open. 2015;5(12). https://doi.org/10.1136/bmjopen-2015-008589 PMid:26644120 PMCid:PMC4679893
2. Petcharat M, Liehr P. Mindfulness training for parents of children with special needs: Guidance for nurses in mental health practice. Journal of Child and Adolescent Psychiatric Nursing. 2017;30(1):35-46. https://doi.org/10.1111/jcap.12169 PMid:28449389
3. Tavousi M, Mehrizi A, Solimanian A, Sarbandi F, Ardestani M, Hashemi A, et al. Health literacy in Iran: findings from a national study. Payesh (Health Monitor). 2016;15(1):95-102.
4. Jafari Y, Vahedian-Shahroodi M, Tehrani H, Esmaily H, Haresabadi M, Shariati M. The relationship between caregivers' health literacy and the behavior of women with Multiple Sclerosis. The Iranian Journal of Obstetrics, Gynecology and Infertility. 2018;21(7):64-71.
5. Sanders LM, Federico S, Klass P, Abrams MA, Dreyer B. Literacy and child health: a systematic review. Archives of pediatrics & adolescent medicine. 2009;163(2):131-40. https://doi.org/10.1001/archpediatrics.2008.539 PMid:19188645
6. Paschal AM, Mitchell QP, Wilroy JD, Hawley SR, Mitchell JB.

Parent health literacy and adherence-related outcomes in children with epilepsy. Epilepsy & Behavior. 2016;56:73-82. https://doi.org/10.1016/j.yebeh.2015.12.036 PMid:26851644

7. Janisse HC, Naar-King S, Ellis D. Brief report: parent's health literacy among high-risk adolescents with insulin dependent diabetes. Journal of pediatric psychology. 2010;35(4):436-40. https://doi.org/10.1093/jpepsy/jsp077 PMid:19755494 PMCid:PMC2858438
8. Gardiner P, Dvorkin L. Promoting medication adherence in children. American family physician. 2006;74(5):793-8.
9. Miskulin M, Simic I, Bilic-Kirin V, Mujkic A, Berlancic T, Miskulin I. Health literacy as a predictor of road traffic injury prevention. European Journal of Public Health. 2020;30(Supplement_5):ckaa166. 976. https://doi.org/10.1093/eurpub/ckaa166.976
10. Bergman-Evans B. AIDES to improving medication adherence in older adults. Geriatric Nursing. 2006;27(3):174-82. https://doi.org/10.1016/j.gerinurse.2006.03.003 PMid:16757389
11. Charoghchian Khorasani E, Tavakoly Sany SB, Tehrani H, Doosti H, Peyman N. Review of Organizational Health Literacy Practice at Health Care Centers: Outcomes, Barriers and Facilitators. International journal of environmental research and public health. 2020;17(20):7544. https://doi.org/10.3390/ijerph17207544 PMid:33081335 PMCid:PMC7589923
12. Abrams EM. The Impact of Caregiver Health Literacy on Pediatric Asthma: An Integrative Review. Pediatric Allergy, Immunology, and Pulmonology. 2020;33(3):110-6. https://doi.org/10.1089/ped.2020.1192
13. Dey M, Wang J, Jorm AF, Mohler-Kuo M. Children with mental versus physical health problems: differences in perceived disease severity, health care service utilization and parental health literacy. Social psychiatry and psychiatric epidemiology. 2015;50(3):407-18. https://doi.org/10.1007/s00127-014-0944-7 PMid:25085110
14. Chehri M. Assessing the health literacy level of parents of preschool children. journal of Pediatric Nursing . 2015;4(1):1-10.
15. Mozafari M, Borji M. Assessing the health literacy level of parents in School children ilam in 2015. Journal of Nursing Education. 2017;5(6):53-61. https://doi.org/10.21859/jne-05068
16. Shahbazi M, Mortazavi Z, Nazemi Z, Ezzati-Rastegar K, Mortazavi S-s. The Health Literacy of Employees in Educational-Rehabilitation Centers Affiliated to The Welfare Organization. Journal of Health Literacy. 2021;5(4):48-55.
17. Bathory E, Tomopoulos S, Rothman R, Sanders L, Perrin EM, Mendelsohn A, et al. Infant sleep and parent health literacy. Academic pediatrics. 2016;16(6):550-7. https://doi.org/10.1016/j.acap.2016.03.004 PMid:26979779 PMCid:PMC4975997
18. Hassan K, Heptulla RA. Glycemic control in pediatric type 1 diabetes: role of caregiver literacy. Pediatrics. 2010;125(5):e1104-e8. https://doi.org/10.1542/peds.2009-1486 PMid:20368322
19. Glick A, Marquez K, Migotsky M, Dreyer B, Tomopoulos S, Fierman A, et al. 3464 Readability, Understandability, and Actionability of Inpatient Discharge Instructions: A Health Literacy Perspective. Journal of Clinical and Translational Science. 2019;3(s1):94-. https://doi.org/10.1017/cts.2019.214 PMCid:PMC6799280
20. Keim-Malpass J, Letzkus LC, Kennedy C. Parent/caregiver health literacy among children with special health care needs: a systematic review of the literature. BMC pediatrics. 2015;15(1):92. https://doi.org/10.1186/s12887-015-0412-x PMid:26242306 PMCid:PMC4525748
21. Samadibeyk M. National study on the prevalence of autism in five-year-old children in Iran. Autism Journal. 2013;16(1):5-14. https://doi.org/10.1177/1362361311407091 PMid:21610190
22. Kharazi SS, Peyman N, Esmaily H. Association between maternal health literacy level with pregnancy care and its outcomes. The Iranian Journal of obstetrics, Gynecology and infertility. 2016;19(37):40-50.
23. SaeediKoupai M, Motaghi M. Comparing health literacy in high school female students and their mothers regarding womens health. Journal of Health Literacy. 2017;1(4):220-9.
24. Pati S, Siewert E, Wong AT, Bhatt SK, Calixte RE, Cnaan A. The influence of maternal health literacy and child's age on participation in social welfare programs. Maternal and child health journal. 2014;18(5):1176-89. https://doi.org/10.1007/s10995-013-1348-0 PMid:23990157 PMCid:PMC3938979