Original Article

The Health Literacy and Self-efficacy Levels of Parents of Patients with Spinal Muscular Atrophy

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Abstract

Purpose: This study aims to determine the self-efficacy and health literacy levels of parents of patients diagnosed with spinal muscular atrophy (SMA).

Design and Methods: This is a descriptive and correlational study. Its population included 126 parents of children diagnosed with SMA who visited the Hospital from August 1, 2018 to May 9, 2019. The sample consisted of 90 parents whose children were diagnosed with SMA who met the inclusion criteria. Data were collected using a sociodemographic information form, the Turkish Health Literacy Survey (THLS-32) and the General Self-efficacy Scale (GSES). The data were analyzed using numbers, percentages, minimum and maximum values, means, standard deviations, and Pearson's correlation analysis.

Findings: The parents' mean score on the GSES was 46.18±9.26. Their highest subscale score was 23.62± 12.25 on its initiative subscale, their lowest subscale score was 14.00±3.30 on its persistence subscale. Their mean THLS-32 score indicated that 40% of the parents had insufficient levels of health literacy. A positive high level relationship was found between the total scores on the GSES and the THLS-32 (p<0.05).

Nursing practice implications: Health literacy and self-efficacy of parents affect the care they receive**.** It is crucial for nursing care to determine the health literacy and self-efficacy levels of parents of children with SMA and to support them. Nursing care is more effective when parents are supported and included in care

Conclusions: This study found that the parents of patients with SMA had low health literacy and self-efficacy levels, and that health literacy had a positive significant relationship with self-efficacy.

Keywords: Health Literacy, Self-efficacy, Parents of Patients with Spinal Muscular Atrophy

Introduction

Spinal muscular atrophy (SMA) is an autosomal recessively inherited neuromuscular disease that causes irreversible muscle atrophy and is one of the significant causes of the infant and child deaths (Feldman, Grisold, Russell, & Loscher, 2016). Its incidence per 100,000 live births is 5.0 in Poland, 5.8 in Taiwan and 1.2 in Japan (Chien et al.,2017; Okamoto et al.,2019; Verhaart et al.,2017).

Today, radical therapy is not available for SMA (Verhaart et al.,2017). Symptomatic treatment is used to try to reduce symptoms. Effective physical therapy is crucial (Finkel, Bishop, & Nelson,2017). Children with SMA need more parental care than healthy children, which increases parents' responsibilities. Parents of children with SMA experience more difficulties than other parents.

Families of disabled children worry whether they can cope with their situation. They are afraid of making mistakes both in seeking treatment opportunities and in giving care. Therefore, such parents' self-efficacy beliefs, the belief that an individual can initiate an action that can affect events around them and maintain this action until it is concluded, are very important.

Self-efficacy is related to individuals' beliefs in their ability to put the motivation, cognitive resources and behaviors they need to control events in their lives into action (Yıldırım,& İlhan,2010; Yin, Han, & Perron 2020). Self-efficacy beliefs can be improved by previous successful experiences, the success stories of other people who share similar characteristics, positive feedback from other people

and positive moods (Yıldırım,& İlhan,2010; Handiyani et al.2019).

A child with SMA brings lots of responsibilities at birth. Mothers and fathers share these responsibilities. Both medical and physical therapy interventions are crucial for increasing quality of life. Parents have to keep track of the ever-changing and ever-growing field of SMA medical therapy (Cremers,2019; Messsina et al.,2019). There are a number of factors that affect good decision making about health. One of them is health literacy (Lee, et al.,2020). Decisions about disease affect treatment outcomes, the effectiveness of treatment and quality of life. Individuals make these decisions based on their competencies, capacities, and knowledge about health. This indicates the importance of health literacy (Meyers et al.,2020).

Of the adults in the US, 50% do not have basic health literacy (DeWalt, Berkman, Sheridan, Lohr,& Pignone,2004). The United Nations Educational, Scientific Cultural Organization (UNESCO) has reported that 776 million people do not have basic health literacy skills (Nutbeam, 2000), indicating that health literacy levels are low worldwide.

Adequate care cannot be provided because there is a limited number of studies of pediatric palliative care of children with neurological diseases and limited information about parents' requests and beliefs concerning care (Dereli,& Okur,2008). Parents should have sufficient self-efficacy and health literacy levels to provide adequate care.

There are very few studies of the relationship between health literacy and self-efficacy. The literature shows that these two concepts have an impact on positive parenting (Cinar,Ay,& Boztepe,2017).

A study conducted outside of Turkey found a significant relationship between low health literacy levels and low self-efficacy levels (Fong et al.,2018). Health literacy and self-efficacy are significant for health professionals due to their effects on healthy living and quality of life. Nursing care aims for individuals to acquire skills to do daily routines independently. It is more important for parents to take part in care and for care to be holistic when working with pediatric patients. Nurses should also consider individuals' health literacy and self-efficacy levels when establishing communication about healthy lifestyle and active participation in developing medical therapy methods. Nurses have the important responsibilities of determining and increasing the health literacy and self-efficacy levels of parents who are the primary care givers of the patients with SMA. These responsibilities involve including parents in patient care, establishing

communication that takes health literacy and self-efficacy levels into consideration, and giving information about disease symptoms and findings (Fong et al.,2018). Parents of pediatric patients with chronic diseases encounter a variety of problems during treatment, so they should be included in nursing care plans and be supported. Parents' social activities are limited by treatment and care. They may feel helpless, lonely, incompetent about parenting, and hopeless. Nurses should be aware of these feelings and give parents opportunities to express them. Nursing care is more effective when parents are supported and included in care (Geckil, Cetinkaya, & Cabar,2018).

For all these reasons, this study was conducted to determine the self-efficacy and health literacy levels of parents of children diagnosed with SMA. This study is expected to offer insight into nursing care for children diagnosed with SMA.

Research Questions:

What are the self-efficacy levels of the parents of children with SMA?
What are the health literacy levels of the parents of children with SMA?
Do parents' self-efficacy and health literacy levels vary by their sociodemographic characteristics?

Aim:

This study aims to determine the self-efficacy and health literacy levels of parents of patients diagnosed with spinal muscular atrophy (SMA).

Design and Methods

Design: This is a descriptive and correlational study.

Study Setting: This study was conducted in the Pediatric Neurology Polyclinic and Pediatric Neurology Service of Hospital from August 1, 2018 to May 9, 2019.

Study population and sample: The population included the parents of children diagnosed with SMA who visited the Hospital. Individuals who did not agree to participate in the study or did not meet its inclusion criteria were not included. The sample consisted of 90 parents.

Inclusion Criteria: This study included:individuals who were older than 18 years old, whose children were diagnosed with SMA, who had no communication problems and who had no history of mental disorders.

Data Collection Tools: The data were collected using a sociodemographic information form, the General Self-efficacy Scale and the Turkish Health Literacy Survey (THLS-32). The data were collected

in face-to-face interviews that lasted roughly 20 minutes.

Personal Information Form: This form has seven questions about age, gender, education levels and income levels, and occupation.

The Turkish Health Literacy Survey (THLS-32): The European Health Literacy Survey Questionnaire was developed by the HLS-EU Consortium in 2012. Abacıgil (2016) did the translation and adaptation of this survey into Turkish in 2016. The survey is used to determine the health literacy levels of individuals older than 15. This Likert-type survey has 32 items in 2 dimensions: health care, and disease prevention and health promotion, and its conceptual framework differs from that of the original survey. It includes four aspects of health literacy: accessing health information, understanding it, evaluating it and applying it. Its configuration is based on a 2x4 matrix. Its type 1 error rate is 0.05. The internal consistency coefficient of the survey was 0.927. The items are scored: 1=very easy, 2=easy, 3=difficult, 4=very difficult, and 5=do not know. Possible scores on the survey range from 0 to 50 (Okyay and Abacıgil 2016). The Cronbach's alpha coefficient of the THLS-32 was 0.90 in this study.

The General Self-efficacy Scale: Yıldırım and Ilhan (2010) did the adaptation and validity and reliability study of its Turkish version in 2010 (Yildirim and Ilhan 2010). The Turkish version has 17 items in 3 subscales: initiative, effort and persistence. This five-point Likert-type scale asks the respondents say how well the items describe them, and the responses range from never to always. Items 2, 4, 5, 6, 7, 10, 11, 12, 14, 16 and 17 are reverse scored. The lowest possible score is 17, and the highest is 85. Higher scores indicate higher self-efficacy beliefs. The Cronbach's alpha coefficient of this scale was 0.88. The Cronbach's alpha coefficient of the GSES was 0.98 in this study.

Data evaluation: The data were analyzed using SPSS for Windows 17 software (Figure 1). Numbers, percentages, minimum and maximum values, means, and standard deviations as well as the statistical analyses in the table below were used in the data analysis (Figure 2). The dependent variables were the parents' mean scores on the health literacy and general self-efficacy scales and subscales. The independent variables were the parents' sociodemographic characteristics.

Ethical aspects of study: Prior to the study, ethics committee approval and written permission were obtained from the University Faculty of Nursing Ethics Committee (Appendix 3) and the University Hospital (Appendix 4). Prior to data collection, the researchers followed the ethical informed consent principle and informed the parents about the study's aim and duration and ongoing procedures throughout the study process to protect their rights. The researchers also followed the ethical principles of respect for human dignity and autonomy by explaining that they were allowed to withdraw from the study at any time, and that their confidentiality, anonymity and personal data would be protected.

Limitations of the Study: This study was carried out with the parents of children who were being treated at a single hospital for a limited time.

Generalizability of the Study: The conclusions of this study can only be generalized to the parents of the patients with SMA who participated in it.

Results

Here are this study's results: Table 1 shows the parents' demographic characteristics. Table 2 shows that the participants' scores on the subscales of initiative, effort, persistence and on the entire self-efficacy scale were 23.62±12.25, 13.54±1.55, 8.59±3.30 and 46.18±9.26, respectively. The participants scored 28.18±12.87 on the subscale of health care, 30.34±12.73 on the subscale of disease prevention and health promotion, and 29.26±12.68 on the entire HLS.Of the parents, 41.1% had inadequate health literacy scores on the health care subscale, 41.1% had inadequate scores the disease prevention and health promotion subscale, and 40% had inadequate scores on the entire scale (Table 2). Table 3 shows that age had a positive low level significant relationship with the initiative subscale score and the entire GSES score (p<0.05). Age had a negative low level significant relationship with the scores on the persistence subscale, health care subscale, disease prevention and health promotion subscale, and the entire THLS score (p<0.05). Initiative subscale and total GSES scores increased with age, and persistence subscale, health care subscale, disease prevention and health promotion subscale and total THLS scores fell with age.Table 4 shows the relationships between scores on the GSES and its subscales, and scores on the THLS and its subscales.

Table 1. The parents' demographic characteristics

		n	%
Gender	Female	49	54.4
	Male	41	45.6
Education	Primary school	19	21.1
	Middle school	32	35.6
	High school	28	31.1
	University	11	12.2
Marital Status	Married	86	95.6
	Divorced	4	4.4
Occupation	Housewife	39	43.3
	Worker	31	34.4
	Government official	10	11.1
	Teacher	6	6.7
	Other	4	4.4
Income Level	High	22	24.4
	Middle	37	41.1
	Low	31	34.4
Presence of Disease	Yes	22	24.4
	No	68	75.6
Disease Type	Diabetes	7	31.8
	Hypertension	5	22.7
	Cholesterol	1	4.5
	Osteoporosis	1	4.5
	Other	8	36.4
Visual Impairment	Yes	9	10.0
	No	81	90.0
Hearing Impairment	Yes	2	2.2
	No	88	97.8
	n	**Min.**	**Max.**	**Mean**	**SD.**

| **Age** | 90 | 22.00 | 57.00 | 36.34 | 6.51 |

Table 2. The distribution of the parents' THLS-32 and GSES mean scores

		n	Min.	Max.	Mean	SD.
General Self-efficacy Scale	**Initiative**	90	9.00	45.00	23.62	12.25
	Effort	90	10.00	17.00	13.54	1.55
	Persistence	90	3.00	14.00	8.59	3.30
	Total Self-efficacy Score	90	33.00	73.00	46.18	9.26
Health Literacy Survey	**Health Care**	90	5.21	48.96	28.18	12.87
	Disease Prevention and Health Promotion	90	7.29	50.00	30.34	12.73
	General	90	6.25	48.44	29.26	12.68
		Inadequate Health Literacy	**Problematic-Limited Health Literacy**	**Sufficient Health Literacy**	**Excellent Health Literacy**

Health Literacy Survey		n	%	n	%	n	%	n	%
	Health Care	37	41.1	15	16.7	22	24.4	16	17.8
	Disease Prevention and Health Promotion	37	41.1	11	12.2	19	21.1	23	25.6
	General	36	40.0	12	13.3	23	25.6	19	21.1

Table 3. The relationships between age and the GSES, the THLS-32 and their subscale scores

			Age
GSES	**Initiative**	r	0.336
		p	**0.001***
	Effort	r	0.099
		p	0.351
	Persistence	r	-0.352
		p	**0.001***
	Entire Scale Score	r	0.366
		p	**0.000***
THLS-32	**Health care**	r	-0.273
		p	**0.009***
	Disease Prevention and Health Promotion	r	-0.285
		p	**0.006***
	Entire Scale Score	r	-0.282
		p	**0.007***

*(p<0.05)

Table 4. The relationships between scores on the GSES and its subscales, and scores on the THLS and its subscales

	Scales		**THLS**		
			Health Care	**Disease Prevention and Health Promotion**	**General**
General Self-efficacy Scale	**Initiative**	r	0.901	0.893	0.906
		p	**0.000**	**0.000**	0.000*
	Effort	r	0.211	0.277	0.246
		p	**0.046**	**0.008**	0.019*
	Persistence	r	0.879	0.871	0.883
		p	**0.000**	**0.000**	0.000*
		r	0.780	0.741	0.768

Total GSES Score	p	**0.000**	**0.000**	0.000*

*(p<0.05)

Table 4 shows that initiative subscale scores on the GSES had a positive high level significant relationship with the scores on the health care subscale, disease prevention and health promotion subscale, and the entire THLS (p<0.05). The effort subscale score on the GSES had a positive low level significant relationship with the scores on the health care subscale, disease prevention and health promotion subscale, and the entire THLS (p<0.05). The persistence subscale score on the GSES had a positive high level significant relationship with the scores on the health care, disease prevention and health promotion subscales, and the entire THLS (p<0.05). The total GSES score had a positive high level significant relationship with the scores on the health care, disease prevention and health promotion subscales, and the entire THLS (p<0.05).

Discussion

The findings of this study of the health literacy and self-efficacy levels of parents of patients diagnosed with SMA are discussed here in the context of the relevant literature. The parents' minimum and maximum scores on the GSES were below average, and their highest self-efficacy score was on the initiative subscale (Table 2), which indicates positive attitude and high self-efficacy beliefs about taking action against a difficulty or challenge. Trutescu et al. (2018) carried out a study outside of Turkey and found that parents of disabled individuals have lower self-efficacy levels than parents of non-disabled individuals (Trutescu, Popa-Velea, & Dobrescu,2018). Zhou et al. (2019) found that parents of individuals with autism spectrum disorder have low self-efficacy levels (Zhou, Yin, Wang,& Wang,2019). Self-efficacy has a critical place in raising children and people directing their own lives. The feeling of helplessness that parents of children with SMA experience when coping with the disease is thought to reduce their self-efficacy levels. This study's found that most of the parents had inadequate health literacy levels (<25) (Table 2).

Durmaz et al. (2016) found that 91.6% of health care professionals do not know the concept of health literacy (Durmaz, et al., 2016). May et al. (2018) conducted a study in the US and found that 56% of parents of children with an acute disease had inadequate health literacy levels (May et al.,2018). The parents' health literacy rates may have been inadequate because health information is complicated, education levels are low, they lack instructions to change unhelpful behaviors, and SMA is not a well-known disease.

This study found a positive relationship between the parents' age and their health literacy and self-efficacy levels (Table 3, p<0.05). Zhang et al. (2019) found a positive relationship between self-efficacy and age (Zhang, et al., 2019). As Bandura's (1995) self-efficacy theory claims, previous experiences are the basis for self-efficacy (Bandura,1995a). Hayran (2018) found a negative relationship between health literacy and age (Hayran,& Ozer,2018). The reason for this is thought to be that the upper age limit of the participants was higher (≤80). Bozkurt and Demirci (2018) found that individuals older than 65 have low health literacy levels (Bozkurt,& Demirci,2018). Health literacy and self-efficacy levels are thought to increase because experience and health knowledge increase along with age.This study found a positive high level significant relationship between the initiative subscale score on the GSES and the scores on the health care subscale, disease prevention and health promotion subscale and the entire THLS-32 (p<0.05, Table 4). It can be concluded from this study's findings that health literacy score increases as self-efficacy total score increases. The literature review shows that the number of studies of the relationship between health literacy and self-efficacy is not sufficient in Turkey. Ulusoy and Koroglu (2019) reported that self-efficacy has a positive impact on cultural quotient (Ulusoy Yıldırım,& Koroglu,2019). Miller et al. (2018) found a positive significant relationship between health literacy and quality of life (Miller, Cage, Nowachi, Jackson,& Modlin,2018). Lael-Monfared (2019) examined the relationship between health literacy and self-care behaviors and found that healthy lifestyle behaviors increased as health literacy levels increased (Lael-Monfared et al., 2019). Trutescu et al. (2018) found that the self-efficacy levels of parents of children diagnosed with attention deficit and hyperactivity disorder were inadequate (Trutescu, Popa- Velea,& Dobrescu, 2018). Paschal et al. (2016) conducted a study with parents of children with epilepsy and found that their health literacy levels were low (Paschal, et al., 2016). Bathory et al. (2016) found a positive relationship between babies' sleep durations and parents' health literacy levels (Bathory et al.,2016). Ijeoma (2016) performed a study in Canada and found a positive significant relationship

between health literacy and self-efficacy (Ijeoma Ibelo,2016). Health literacy scores increased as self-efficacy scores increased. Fong et al. (2018) found a positive relationship between parents' self-efficacy and health literacy levels (Fong, 2018). Individuals with low self-efficacy levels have less confidence in their abilities and utilize less basic health information and services.

Recommendations: This study found that the parents of patients with SMA had inadequate health literacy scores, and that their general self-efficacy scale scores were low. A positive high level significant relationship was found between their total GSES and THLS scores.

This study recommends that nurses should consider the health literacy and self-efficacy levels of parents

of children with SMA for patients' and their families' education to be effective.Experimental studies of increasing self-efficacy and health literacy levels should be planned and conducted with larger sample sizes in different regions. It is crucial for nursing care to determine the health literacy and self-efficacy levels of parents of children with SMA and to support them.

Nursing Practice Implıcations: Health literacy and self-efficacy of parents affect the care they receive**.** It is crucial for nursing care to determine the health literacy and self-efficacy levels of parents of children with SMA and to support them. Nursing care is more effective when parents are supported and included in care.

Data from the Following Figures Were Used

Figure 1. The statistical tests used for data analysis

	Measurements of normally distributed data	**Measurements of non-normally distributed data**
Comparison of paired groups	Dependent samples t-test	Mann-Whitney U test
Comparison of multiple groups	Analysis of variance (least significant difference was used as the advanced analysis.)	Kruskal-Wallis test
The relationships between the scores on the THLS and its subscales and other variables	Pearson's correlation Analysis	Spearman's correlation analysis
Internal Validity	Cronbach's **α** coefficient	
Variables' normality distribution	Kurtosis and skewness coefficients*	

*(Addapted fron Cokluk, Sekercioglu & Buyukozturk, 2012)

Figure2 shows the variables' normality distribution.

		N	**Skewness**		**Kurtosis**	
		Statistic	**Statistic**	**Std. Error**	**Statistic**	**Std. Error**
	Age	90	0.358	0.254	0.618	0.503
General Self-efficacy Scale	**Initiative**	90	0.514	0.254	-1.299	0.503
	Persistence	90	-0.264	0.254	-1.038	0.503

	Total Self-efficacy Score	90	0.585	0.254	-0.719	0.503
Turkish Health Literacy Survey	**Disease Prevention and Health Promotion**	90	-0.09	0.254	-1.342	0.503
	General	90	-0.115	0.254	-1.275	0.503

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