

PART I. DISEASES AND PROBLEMS DISTINGUISHED BY WHO AND FAO
DZIAŁ I. CHOROBY I PROBLEMY WYRÓŻNIONE PRZEZ WHO I FAO

RELATIONSHIP BETWEEN HEALTH LITERACY AND CARE BURDEN IN MOTHERS
OF CHILDREN WITH CHRONIC CONDITIONS

ZWIĄZEK MIĘDZY ŚWIADOMOŚCIĄ ZDROWOTNĄ A OBCIĄŻENIEM OPIEKĄ
MATEK DZIECI Z CHOROBAMI PRZEWLEKŁYMI

Sinem Yalınzoğlu Çaka^{1(A,B,C,D,E,F)}, Sümeyra Topal^{2(A,D,E,F)}, Işıl Ar^{1(B,D,E)}, Sinem Öztürkler^{1(B,E)}

¹Department of Pediatric Nursing, Faculty of Health Science, Kocaeli University, Kocaeli, Türkiye

²Department of Pediatric Nursing, Faculty of Health Science, Kahramanmaraş İstiklal University, Kahramanmaraş, Türkiye

Authors' contribution

Wkład autorów:

- A. Study design/planning
zaplanowanie badań
- B. Data collection/entry
zebranie danych
- C. Data analysis/statistics
dane – analiza i statystyki
- D. Data interpretation
interpretacja danych
- E. Preparation of manuscript
przygotowanie artykułu
- F. Literature analysis/search
wyszukiwanie i analiza literatury
- G. Funds collection
zebranie funduszy

Tables: 3

Figures: 0

References: 35

Submitted: 2023 Aug 15

Accepted: 2023 Sep 8

Published Online: 2023 Sep 15

Summary

Background. The purpose of this study was to examine the relationship between health literacy and caregiving burden in mothers responsible for primary care of chronically ill children.

Material and methods. The study, given a descriptive and analytical design, was conducted between January-May 2023 in Kocaeli province (Türkiye) with mothers (n=131) who had a child diagnosed with a chronic disease for at least one year. Data were collected using the questionnaire, Turkish Health Literacy Scale-32 (THLS-32) and Zarit Burden Scale (ZBS).

Results. The mean age of mothers participating in the study was 36.96±6.56 years. It was found that there was a significant association between the different descriptive characteristics of the mothers participating in the study and the scales. It was found that the mothers had a sufficient level of health literacy (31.3%), with a mean score of 36.00±8.46 on the THLS-32. There is a significant negative correlation ($r=-0.201$; $p=0.022$) between the mean scores of THLS-32 and ZBS of the mothers participating in the study.

Conclusions. As a result of this study, it was found that some demographic characteristics of mothers caring for a child with a chronic illness have an impact on caregiving burden and health literacy. As the mother's health literacy increases, the burden of caregiving decreases. Family caregivers should be involved in designed educational and intervention programs to increase their health literacy and self-efficacy.

Keywords: care burden, health literacy, chronic disease, nursing, child

Streszczenie

Wprowadzenie. Celem niniejszej pracy było zbadanie związku pomiędzy świadomością zdrowotną a obciążeniem opieką matek odpowiedzialnych za podstawową opieką nad dziećmi przewlekle chorymi.

Materiał i metody. Badania, mające charakter opisowo-analityczny, przeprowadzono w okresie od stycznia do maja 2023 roku w prowincji Kocaeli (Turcja) z udziałem matek (n=131) mających dzieci, u których co najmniej rok wcześniej zdiagnozowano chorobę przewlekłą. Dane zebrano przy użyciu kwestionariusza, skali wiedzy zdrowotnej Turkish Health Literacy Scale-32 (THLS-32) i skali obciążenia opieką Zarit Burden Scale (ZBS).

Wyniki. Średni wiek matek biorących udział w badaniu wyniósł 36,96±6,56 lat. Stwierdzono, że istnieje istotny związek pomiędzy różnymi cechami opisowymi matek biorących udział w badaniach a skalami. Stwierdzono, że matki posiadały wystarczający poziom świadomości zdrowotnej (31,3%), ze średnim wynikiem 36,00±8,46 w skali THLS-32. Istnieje istotna ujemna korelacja ($r=-0,201$; $p=0,022$) pomiędzy średnimi wynikami w skali THLS-32 i ZBS matek biorących udział w badaniach.

Wnioski. Na podstawie niniejszych badań stwierdzono, że niektóre cechy demograficzne matek opiekujących się dzieckiem chorym przewlekle mają wpływ na obciążenie opieką i świadomość zdrowotną. Wraz ze wzrostem wiedzy matki na temat zdrowia zmniejsza się obciążenie opieką. Opiekunowie stanowiący rodzinę powinni brać udział w opracowanych programach edukacyjnych i interwencyjnych, aby zwiększyć swoją świadomość zdrowotną i poczucie własnej skuteczności.

Słowa kluczowe: obciążenie opieką, świadomość zdrowotna, choroba przewlekła, pielęgniarstwo, dziecko

Yalınzoğlu Çaka S, Topal S, Ar I, Öztürkler S. Relationship between health literacy and care burden in mothers of children with chronic conditions. Health Prob Civil. 2024; 18(1): 5-15. <https://doi.org/10.5114/hpc.2023.131166>

Address for correspondence / Adres korespondencyjny: Sinem Yalınzoğlu Çaka, Department of Pediatric Nursing, Faculty of Health Science, Kocaeli University, Kabaoğlu, Baki Komsuoğlu Boulevard No. 515, Umuttepe, 41001 İzmit/Kocaeli, Türkiye, e-mail: sinemyalinzoglu@gmail.com, phone: +90 (262) 303 10 00

ORCID: Sinem Yalınzoğlu Çaka <https://orcid.org/0000-0002-1572-7013>, Sümeyra Topal <https://orcid.org/0000-0001-6316-4043>, Işıl Ar <https://orcid.org/0000-0003-2615-158X>, Sinem Öztürkler <https://orcid.org/0000-0002-1686-516X>

Copyright: © John Paul II University in Białą Podlaska, Sinem Yalınzoğlu Çaka, Sümeyra Topal, Işıl Ar, Sinem Öztürkler. This is an Open Access journal, all articles are distributed under the terms of the Creative Commons Attribution-NonCommercial-ShareAlike 4.0 International (CC BY-NC-SA 4.0) License (<http://creativecommons.org/licenses/by-ncsa/4.0/>), allowing third parties to copy and redistribute the material in any medium or format and to remix, transform, and build upon the material, provided the original work is properly cited and states its license.

Introduction

A chronic disease is a condition that requires monitoring, treatment, protection and lifelong support [1]. Chronic illnesses in children have increased significantly in the last two decades. Epidemiologic studies suggest that as many as 1 out of 4 children in the U.S. suffer from a chronic disease [2]. In general, prevalence estimates vary between 10% and 30%, with the main cause being a lack of established criteria for the classification of chronic disease in pediatrics [2,3].

Technological developments and improvements in the global healthcare system have increased the survival rates of individuals with chronic diseases by supporting outpatient treatment services. Therefore, a significant part of the necessary care continues at home [3,4]. Parents are the most important caregivers for chronically ill children and adolescents [5]. When a child is diagnosed with a chronic illness or disability, this not only has a negative impact on the patient, but also on the physical, psychological, and social well-being of the caregivers [6]. According to the literature, parents of chronically ill children experience sleep disturbances, impairments in family and social communication, and losses in quality of life. Parents' psychological status and coping methods may have an impact on parent-child interactions and the quality of care they provide [5-7]. The burden of care is another consequence of caring for patients with chronic illnesses. The burden of care, which is the physical, psychological and social response of caregivers to the act of caring, occurs due to an imbalance between the demands for care and other responsibilities, such as personal/social duties and work and family roles [7]. A previous study reported that caregiver burden leads to depression, social isolation, burnout, physical disorders, and financial concerns [4,5,7].

In 2018, the World Health Organization defined health literacy as the ability of individuals to "gain access to, understand and use information in ways which promote and maintain good health" [8]. Health literacy influences health outcomes in terms of access to health services, interactions between patients and healthcare providers, and self-care [9]. Among adults, limited health literacy (poor ability to acquire, evaluate and integrate information) compared with individuals with functional health literacy is a key indicator of negative health outcomes such as unhealthy living conditions, lack of information about chronic conditions, limited shared decision making, difficulty understanding educational interventions, difficulty adhering to treatments, increased medication errors, and increased health care spending [10]. While the literature related to the concept of health literacy has received attention in adults with chronic conditions, it has been much less studied in parents of children. Fewer studies have examined health literacy in parents/ caregivers with chronic conditions, despite their particular vulnerability to inadequate information sharing, management of complex home medication regimens, and confusion about treatment protocols and nonadherence to medications or advice [11-13]. In addition, the chronicity of their diagnosis makes it particularly important to assess health literacy in parents and caregivers throughout the treatment process. This gap in assessment and knowledge of the negative consequences of caregiver/parent health literacy on children with chronic conditions is of particular concern and may guide future research.

Aim of the work

Therefore, the aim of this study is to examine the relationship between health literacy and caregiver burden in mothers responsible for primary care of children who have had chronic diseases for at least one year or longer.

Material and methods

Study design and participants

It is a descriptive and analytical study. The study was conducted between January-May 2023 with the mothers of children with chronic illnesses who applied to the outpatient clinics and wards in the Department of Pediatrics at Kocaeli University Hospital, Türkiye.

The population of the research consisted of mothers with children with chronic diseases who received inpatient or outpatient treatment in the hospital. In order to generalize the research results, the size of the sample was determined using Gpower 3.9.1. The minimum number of participants required to be statistically significant for a weak correlation coefficient ($r=0.30$) between the two scale scores was calculated as 112 mothers ($\alpha=0.05$, $1-\beta=0.90$). In order to achieve high inference power in the study, an attempt was made to reach all mothers who met the inclusion criteria within the relevant date range. 145 mothers were reached, but 14 participants who filled out the survey incompletely were excluded from the study and the study was conducted with a total of 131 mothers.

Inclusion criteria:

- a child who has been diagnosed with a chronic disease for 1 year or more,
- not having a problem with communication skills,
- being a mother aged 18 years and over, caring for a child with chronic disease,
- voluntarily accepting the study.

Exclusion criteria:

- mothers with a health-related professional occupation,
- mothers without Turkish reading and comprehension skills.

Ethical dimension of the study

The approval from Kocaeli University Ethics Committee (Approval No: KÜ GOKAEK-2022/20.29) and the necessary institutional authorization from the relevant university administration had been obtained before the study was conducted. After being informed of the aim of the study, the use of the data, and the confidentiality of the responses, mothers whose written consent was obtained were included in the sample.

Data collection

The data were collected face-to-face using the Questionnaire Form, Turkish Health Literacy Scale-32, and Zarit Burden Scale prepared by the researchers. The participants were taken to a calm and quiet room and given data collection forms by the researchers and asked to fill them in. The data collection process took approximately 20 minutes.

Questionnaire form

In this section, there are 14 questions developed by the researchers in line with the literature and including the socio-demographic characteristics of the participants. These questions consist of questions related to age, educational status, employment status, economic level, etc.

Turkish Health Literacy Scale-32 (THLS-32)

The Health Literacy Scale (HLS-EU) was developed by the European Health Literacy Research Consortium in 2012 [14]. The Turkish Health Literacy Scale-32 (THLS-32) was developed by Abacigil et al. [15] with the HLS-EU adapted into Turkish. The THLS-32 scale is a 5-point Likert scale consisting of 32 questions [15]. In evaluating the scale, the indices were normalized to a value between 0 and 50, as in HLS-EU. After calculation, 0 represents the lowest health literacy score and 50 the highest. Based on the calculated scores, health literacy is divided into four categories. THLS-32 is structured as a 2X4 matrix taking two basic dimensions. Accordingly, the matrix consists of a total of eight components, two dimensions (treatment and service, disease prevention and health promotion) and four processes (access to information, understanding information, information assessment, information use and application). Cronbach's alpha coefficient was 0.93, 0.88 for the first dimension and 0.86 for the second dimension for the overall scale. The reliability coefficient for this study is 0.93.

Zarit Burden Scale (ZBS)

The scale was developed in 1980 by Zarit et al. [16]. The scale used to examine the problems experienced by the individual in need of care and by the caregivers is a scale consisting of 22 statements that determine the effect of caregiving on the person's life. The Likert-type scale ranges from 0 to 4 as "never, rarely, sometimes, quite often or almost always". The lowest score that can be obtained from the scale is 0 and the highest score is 88. A total score of 88-61 is considered as severe burden, 60-41 as moderate burden, 40-21 as mild to moderate burden, and less than 21 as little or no burden; a high scale score indicates that the distress experienced is high. The validity study of the Zarit Burden Scale (ZBS) was conducted by İnci in 2006 [17]. The internal consistency coefficient of the scale ranged between 0.87 and 0.94 and test-retest reliability of 0.90 were found. In this study, Cronbach alpha coefficient was 0.84.

Statistical analysis

The study data were completed using the IBM SPSS Statistics 23 (Statistical Package for Social Sciences) program. Descriptive analyses are presented as percentage, mean and standard deviation. In addition, whether there is a difference between the variables in terms of measurements was tested by independent sample t test, if the number of groups was two, and by one-way analysis of variance (ANOVA) if the number of groups was more than two. Pearson correlation analysis was used to examine the relationship between the scales. $P < 0.05$ was accepted for significance.

Results

The findings of the mothers participating in the study are provided in Table 1. The mean age of the mothers was 36.96 ± 6.56 years. Among the mothers included in the study, 22.1% were university graduates, 84% were housewives, 82.4% had nuclear families, and 67.2% had been married for 10 years or more. In addition, 57.3% had only one child, 51.1% stated that the gender of the child was male and 53.4% stated that they had someone to support them (Table 1).

Table 1. Comparison of the differences between the scales and sociodemographic variables according to group (n=131)

Variables		n	%	ZBS Mean±SD	THLS-32 Mean±SD	Treatment and service Mean±SD	Disease prevention and health promotion Mean±SD
Mother's age	19-35	93	71.0	34.23±13.07	99.81±16.14	51.11±8.20	48.69±9.22
	36 and above	38	29.0	31.23±12.01	104.31±16.29	52.55±7.95	51.76±9.15
	t/p	-	-	1.219/0.225	-1.443/0.151	-0.916/0.362	-1.729/0.086
Educational status	Primary school (1)	74	56.5	32.82±11.87	97.56±15.67	49.78±7.98	47.78±9.13
	Secondary school (2)	28	21.4	32.71±13.99	103.67±18.19	52.60±8.97	51.07±10.08
	High school (3)	29	22.1	35.37±14.11	107.72±13.47	54.96±6.43	52.75±7.90
	F/p	-	-	0.457/0.634	4.769/0.010* ^a	4.807/0.010* ^a	3.589/0.030* ^a
Perceived economic level	Income less than expense (1)	51	38.9	37.74±13.81	98.88±18.28	50.41±8.90	48.47±10.41
	Income equivalent of expense (2)	68	51.9	31.29±11.35	101.41±14.61	51.72±7.50	49.69±8.42
	Income more than expense (3)	12	9.2	26.50±10.83	109.00±14.466	55.25±7.52	53.75±8.20
	F/p	-	-	6.031/0.003** ^{b,c}	1.931/0.149	1.778/0.173	1.596/0.207
Place of residence	Village (1)	7	5.3	38.57±16.23	103.42±16.31	50.57±10.04	52.85±8.23
	District (2)	90	68.7	32.94±12.89	101.45±16.78	51.63±8.42	49.82±9.30
	City (3)	34	26.0	33.41±11.97	99.76±15.15	51.47±7.08	48.29±9.44
	F/p	-	-	0.624/0.538	0.205/0.815	0.056/0.946	0.791/0.455
Family type	Nuclear family	108	82.4	33.94±13.15	101.61±17.13	51.80±8.49	49.80±9.68
	Extended family	23	17.6	30.65±10.88	98.82±11.21	50.26±6.15	48.56±7.14
	t/p	-	-	1.121/ 0.264	0.745/0.458	-0.826/0.410	0.581/0.562
Marriage duration	<10 years	43	32.8	34.00±11.20	100.20±17.17	51.20±8.63	49.00±10.09
	≥10 years and above	88	67.2	33.05±13.56	101.56±15.86	51.69±7.91	49.87±8.89
	t/p	-	-	0.395/0.694	-0.448/0.655	-0.319/0.750	-0.505/0.614
Employment status	Employed	21	16.0	31.14±12.90	103.71±14.49	53.14±7.63	50.57±7.99
	Housewife	110	84.0	33.79±12.79	100.62 ±16.58	51.22 ±8.21	49.40±9.52
	t/p	-	-	-0.868/0.387	0.796/0.427	0.989/0.324	0.529/0.598
Number of living children	First	75	57.3	34.97±13.43	104.41±15.84	52.94±8.37	51.46±8.50
	2 and more	56	42.7	31.21±11.68	96.71±15.88	49.64±7.45	47.07±9.74
	t/p	-	-	1.674/0.097	2.749/0.007**	2.340/0.021*	2.750/0.007**
Infant's sex	Female	64	48.9	34.59±13.98	100.03±17.61	50.89±8.44	49.14±10.49
	Male	67	51.1	32.19±11.55	102.16±14.89	52.14±7.83	50.01±8.00
	t/p	-	-	1.073/0.285	-0.749/0.455	-0.885/0.378	-0.538/0.592

Variables		n	%	ZBS Mean±SD	THLS-32 Mean±SD	Treatment and service Mean±SD	Disease prevention and health promotion Mean±SD
Type of chronic illness	Endocrine system diseases	22	16.8	37.50±14.90	99.13±12.86	50.22±7.13	48.90±6.69
	Neurological diseases	27	20.6	34.48±10.12	97.88±15.42	49.59±8.10	48.29±9.50
	Chromosomal disorders	15	11.5	35.73±15.30	101.93±16.85	51.60±7.98	50.33±9.63
	Urinary system and renal diseases	16	12.2	27.43±12.17	101.43±15.92	51.43±7.71	50.00±9.19
	Hematological diseases	14	10.7	36.71±14.92	108.78±14.39	55.92±6.77	52.85±8.16
	Oncological diseases	19	14.5	33.15±12.26	100.68±24.40	51.15±11.73	49.52±13.23
	Respiratory system and immunological diseases	18	13.7	27.55±7.89	101.94±11.54	53.05±5.41	48.88±7.98
	F/p	-	-	1.931/0.081	0.760/0.603	1.153/0.336	0.424/0.862
Presence of support person	Yes	70	53.4	31.67±12.50	99.74±15.43	50.98±7.20	48.75±9.33
	No	61	46.6	35.31±12.96	102.70±17.13	52.16±9.10	50.54±9.19
	t/p	-	-	-1.633/0.105	-1.041/0.300	-0.826/0.410	-1.099/0.274

Notes: F – one-way ANOVA test, t – independent sample t test, * $p < 0.05$, ** $p < 0.001$, a – 3>1, b – 1>2, c – 1>3.

There is no statistically significant difference between the scales of age, place of residence, family types, duration of marriage, employment status, gender of the child, type of chronic disease and presence of a support person of the mothers ($p > 0.05$), while there is a statistically significant difference between the scales of educational level, perceived economic level and number of children ($p < 0.05$). Accordingly, the mean scores of those with university education levels in THLS-32 and its sub-dimensions are higher than those with primary/secondary education levels ($p < 0.05$). The mean scores of those who stated that their perceived economic level was low compared to their income and expenditure were higher than those whose income was equal to their expenditure and high ($p < 0.05$). The mean scores of those with only one child in THLS-32 and its sub-dimensions are higher than those with 2 or more children ($p < 0.05$) (Table 1).

When the health literacy levels of the participants were evaluated, it was found that 31.3% (n=41) were at an adequate level. When the burden of care scores were compared according to the health literacy level of the mothers, it was found that the mean burden of care score of those with insufficient level was 39.50±12.59 and the difference was not statistically significant ($p > 0.05$) (Table 2).

Table 2. Comparison of care burden scores by health literacy level of mothers

Health literacy level	n	%	ZBS		F	p
			Mean	Standard deviation		
Insufficient	12	9.2	39.50	12.59	1.546	0.206
Limited/problematic	40	30.5	34.57	10.74		
Sufficient	41	31.3	32.60	13.67		
Perfect	38	29.0	30.97	13.59		

Notes: F – one-way ANOVA test.

When the relationship between the age of the mothers and their children's disease history, the scales and their sub-dimensions were analyzed, no significant relationship was found between the age of the mother, the duration of the child's disease and the frequency of hospitalization within one year and the scales. It was found that there was a significant negative correlation between ZBS and THLS-32 and its sub-dimensions of the mothers participating in the study ($p < 0.05$). Accordingly, it can be said that the burden of care decreases as the mother's health literacy and its sub-dimensions of treatment and service and disease prevention/health promotion literacy increase ($r = -0.201$; $p = 0.022$) (Table 3).

Table 3. Relationship between participants' age and health care variables, disease history, scales and sub-dimensions

Variables		1	2	3	4	5	6	7
Mother age (year)	r	1	-	-	-0.097	0.134	0.136	0.115
	p	-	-	-	0.270	0.128	0.120	0.191
Years since chronic illness diagnosis (year)	r	-	1	-	0.072	0.097	0.079	0.101
	p	-	-	-	0.413	0.271	0.372	0.253
Frequency of hospitalization in a year (number)	r	-	-	1	0.024	0.052	0.046	0.051
	p	-	-	-	0.786	0.552	0.598	0.561
ZBS	r	-	-	-	1	-0.201	-0.188	-0.187
	p	-	-	-	-	0.022*	0.031*	0.033*
THLS-32	r	-	-	-	-	1	0.924	0.942
	p	-	-	-	-	-	0.000**	0.000**
Treatment and service	r	-	-	-	-	-	1	0.743
	p	-	-	-	-	-	-	0.000**
Disease prevention and health promotion	r	-	-	-	-	-	-	1
	p	-	-	-	-	-	-	-

Notes: r – Pearson's correlation analysis, * $p < 0.05$, ** $p < 0.001$.

Discussion

Childhood chronic illnesses are increasing gradually and they are an important health problem in many countries of the world. The care and treatment of chronic illnesses continue at home in addition to the hospital. The parents, having many responsibilities, such as home care of the child, were further burdened by symptom follow-up, management of the treatment process and planning of daily life activities during the long treatment process [1,5,7]. Therefore, the need for parents to have sufficient knowledge, skills and confidence in caring for their relatives should be taken into account [18]. Health literacy includes many elements, such as understanding medical treatment instructions, consent forms, patient education materials, etc., but for an

individual with chronic illnesses and their parents, it also includes understanding needs and being able to manage the disease, including recognizing disease-specific signs and symptoms [12,18].

In this study, no significant association was found between the age of the mothers, the duration of the child's illness, the frequency of hospitalization within a year, and the scale, whereas the burden of care decreased as the health literacy of the mothers increased. In examining the studies on this topic, it appears that the age of the caregiver, the duration of the illness, and the frequency of hospitalizations influence the burden of caregiving [19-23]. However, most of these studies were conducted on adult patients [20,21]. Additionally, it was observed that the patient group receiving care was bedridden or physically disabled [22,23]. In our study, as was not the case in other studies, the patients had no physical disability. This may be a factor that reduces the burden of care and increases health literacy. The literature examining two scales together in mothers of children with chronic illnesses is limited. In a study conducted by Aldawsare, it was found that the health literacy of caregivers of individuals with chronic illnesses and the duration of the disease had a strong effect on the burden of care [11]. Another study found a negative relationship between health literacy and caregiver burden [20]. Mothers often have to interact with health professionals for their children living with chronic illnesses. Such interactions may in themselves increase the mother's level of health literacy, which in turn may encourage increased access to services that can subsequently reduce the burden of care.

When the relationship between THLS-32, which constitutes another dimension of the study, and some sociodemographic variables are examined, many studies emphasize that the level of health literacy of parents is important in improving the health status and care of children [11,12,24]. In this context, in our study, it was determined that mothers had a sufficient level of health literacy (31.3%). Although Aldawsare's study of mothers with children with chronic disease residing in four different centers had similar results [11], in a study conducted with 281 mothers of children diagnosed with chronic asthma in the USA, it was found that health literacy was low [25]. Again, in a study conducted with the parents of children born with congenital sickle cell anemia, it was found that the health literacy of the families was above the average [18]. In other studies conducted with mothers admitted to the hospital with an acute illness, health literacy was found to be limited [24-26]. When these results were analyzed, it was suggested that the high level of health literacy in our study could be related to the presence of multiple types of chronic illnesses and the long duration of the disease. In this study, it is seen that health literacy increases as the level of education increases. The results from different countries are consistent with those of our study [27-29]. Low levels of education and health literacy are important barriers to chronic disease treatment and management. Many studies have shown that these individuals are less likely to use primary care services, more likely to be hospitalized, to use emergency services, and to be on sick leave because of the development of complications [29,30]. Appropriate intervention programs for individuals with low health literacy can improve health outcomes for caregivers and recipients.

When we analyzed the relationship between the ZBS, which constitutes another dimension of the study, and some sociodemographic variables, it was determined that the care burden of mothers was at a mild to intermediate level. While in a study conducted by Adib-Hajbaghery and Ahmadi with parents of chronically ill children, 47% of caregivers reported that they experienced a moderate caregiving burden, in similar studies, parents expressed that they experienced moderate difficulties [31-33]. The reason for this situation can be considered as a result of the fact that the care given by the parents is seen as a parental role and they act with the aim of helping their child. In addition, it is seen that the burden of caregiver mothers with low perceived economic status is higher. When the literature is examined in Türkiye, Türe et al. found that the low income level of mothers with children with chronic illnesses affected the burden of care, Doğan et al. found that the burden of care of caregivers experiencing economic difficulties was significantly moderate to severe [34,35]. The higher burden of caregiving scores of families with poor economic status may be considered to increase

the burden that mothers, who are already physically, socially and emotionally challenged, have to cope with by adding the financial difficulties they experience in meeting the basic needs of their children. In addition, the frequency of hospitalization and the financial burden of medical treatments depending on the type of disease may also increase the burden of care. There is a need for more large-scale studies to examine illnesses comparatively in this regard.

Study limitations

This study has some limitations. First, the study was conducted in a single center and therefore may not be generalizable to all mothers caring for chronically ill children. In addition, the data were analyzed according to the personal responses (self-reporting) by the mothers to the questions on the measurement instrument.

Conclusions

As a result, in our study, it is seen that mothers caring for children with chronic illnesses have adequate health literacy levels and their care burden is at a mild to moderate level. In parallel with this, it was found that increasing the level of health literacy of mothers had a positive contribution to reducing the burden of care. It is important for nurses, whose role as caregivers is at the forefront, to determine the burden of care of mothers, to provide support in the areas they need (social/economic) and to contribute to more effective management of the disease by increasing the level of health literacy. However, there is a need for larger-scale studies at the regional and cultural level, specific to different parameters that may affect health literacy and the burden of care. At the same time, as it may be difficult to generalize to all chronic conditions when developing specific health literacy interventions to improve care and reduce the overall burden of care, future studies recommend health literacy interventions specific to the type of chronic disease. Another factor is that mothers should be sufficiently health-literate so that they can understand basic health information and develop appropriate self-care behaviors that can improve their health status/quality of life.

Disclosures and acknowledgements

The authors declare no conflicts of interest with respect to the research, authorship, and/or publication of this article. This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors. Artificial intelligence (AI) was not used in the creation of the manuscript.

References:

1. Yigitalp G, Surucu HA, Gumus F, Evince E. Predictors of caregiver burden in primary caregivers of chronic patients. *International Journal of Caring Sciences*. 2017; 10: 1168-77.
2. Compas BE, Jaser SS, Dunn MJ, Rodriguez EM. Coping with chronic illness in childhood and adolescence. *Annual Review of Clinical Psychology*. 2012; 8: 455-480. <https://doi.org/10.1146/annurev-clinpsy-032511-143108>
3. Denny S, de Silva M, Fleming T, Clark T, Merry S, Ameratunga S, et al. The prevalence of chronic health conditions impacting on daily functioning and the association with emotional well-being among a national sample of high school students. *Journal of Adolescent Health*. 2014; 54(4): 410-415. <https://doi.org/10.1016/j.jadohealth.2013.09.010>
4. Chen HM, Huang MF, Yeh YC, Huang WH, Chen CS. Effectiveness of coping strategies intervention on caregiver burden among caregivers of elderly patients with dementia. *Psychogeriatrics*. 2015; 15: 20-25. <https://doi.org/10.1111/psyg.12071>

5. Macedo EC, da Silva LR, Paiva MS, Ramos MNP. Burden and quality of life of mothers of children and adolescents with chronic illnesses: an integrative review. *Revista Latino-Americana de Enfermagem*. 2015; 23: 769-777. <https://doi.org/10.1590/0104-1169.0196.2613>
6. Elmore D. The impact of caregiving on physical and mental health: implications for research, practice, education, and policy. In: Talley RC, Fricchione GL, Druss BG., editors. *The challenges of mental health caregiving*. New York: Springer; 2014. https://doi.org/10.1007/978-1-4614-8791-3_2
7. Mikolajczak M, Brianda ME, Avalosse H, Roskam I. Consequences of parental burnout: Its specific effect on child neglect and violence. *Child Abuse & Neglect*. 2018; 8: 134-145. <https://doi.org/10.1016/j.chiabu.2018.03.025>
8. World Health Organization (WHO). Health Promotion [Internet]. Geneva: WHO; 2018 [access 2022 Nov 29]. Available from: <https://www.who.int/healthpromotion/en>
9. Paasche-Orlow MK, Wolf MS. The causal pathways linking health literacy to health outcomes. *American Journal of Health Behavior*. 2007; 31(1): 19-26. <https://doi.org/10.5993/AJHB.31.s1.4>
10. DeWalt DA, Hink A. Health literacy and child health outcomes: a systematic review of the literature. *Pediatrics*. 2009; 124(3): 265-274. <https://doi.org/10.1542/peds.2009-1162B>
11. Aldawsare M. Correlates of health literacy and perceptions of burden among caregivers of persons diagnosed with chronic illnesses. [dissertation]. San Diego: University of San Diego; 2022.
12. Sanders LM, Shaw JS, Guez G, Baur C, Rudd, R. Health literacy and child health promotion: implications for research, clinical care, and public policy. *Pediatrics*. 2009; 124(Suppl. 3): 306-314. <https://doi.org/10.1542/peds.2009-1162G>
13. Yin HS, Johnson M, Mendelsohn AL, Abrams MA, Sanders LM, Dreyer, BP. The health literacy of parents in the United States: a nationally representative study. *Pediatrics*. 2009; 124(Suppl. 3): 289-S298. <https://doi.org/10.1542/peds.2009-1162E>
14. HLS-EU Consortium. Comparative report of health literacy in eight EU member states: The European health literacy survey (HLS-EU) [Internet]. 2012 Jul 12 [access 2023 Jun 10]. Available from: https://www.hsph.harvard.edu/wp-content/uploads/sites/135/2015/09/neu_rev_hls-eu_report_2015_05_13_lit.pdf
15. Abacigil F, Harlak H, Okyay P, Evcı Kiraz D, Gursoy Turan S, Saruhan G, et al. Validity and reliability of the Turkish version of the European Health Literacy Survey Questionnaire. *Health Promotion International*. 2018; 34(4): 1-10. <https://doi.org/10.1093/heapro/day020>
16. Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist*. 1980; 20(6): 649-655. <https://doi.org/10.1093/geront/20.6.649>
17. İnci FH, Erdem M. [Validity and reliability of the Burden Interview and its adaptation to Turkish]. *Atatürk Üniversitesi Hemşirelik Yüksekokulu Dergisi*. 2008; 11(4): 85-95 (in Turkish).
18. Shook L, Crosby LE, Atweh GF. Health literacy and sickle cell disease: an assessment of adolescents, young adults and caregivers. *Blood*. 2013; 122(21): 2251. <https://doi.org/10.1182/blood.V122.21.2251.2251>
19. Barutcu CD. Relationship between caregiver health literacy and caregiver burden. *Puerto Rico Health Sciences Journal*. 2019; 38(3): 163-169.
20. Häikiö K, Cloutier D, Rugkåsa J. Is health literacy of family carers associated with carer burden, quality of life, and time spent on informal care for older persons living with dementia?. *PLoS One*. 2020; 15(11): 1-16. <https://doi.org/10.1371/journal.pone.0241982>
21. Spatuzzi R, Giuliatti MV, Ricciuti M, Merico F, Romito F, Reggiardo G, et al. Does family caregiver burden differ between elderly and younger caregivers in supporting dying patients with cancer? An Italian study. *American Journal of Hospice and Palliative Medicine*. 2020; 37(8): 576-581. <https://doi.org/10.1177/1049909119890840>

22. Oni OD, Olagunju AT, Okpataku CI, Erinfolami AR, Adeyemi JD. Predictors of caregiver burden after stroke in Nigeria: effect on psychosocial well-being. *Indian Journal of Psychiatry*. 2019; 61(5): 457. https://doi.org/10.4103/psychiatry.IndianJPsychiatry_395_18
23. Badaru UM, Fatima BS, Ahmad RY, Lawal IU, Ogwumike OO, Usman JS. Influence of duration of caregiving on the burden and quality of life of informal caregivers of stroke survivors. *Indian Journal of Physiotherapy and Occupational Therapy*. 2019; 13(3): 184-190. <https://doi.org/10.5958/0973-5674.2019.00114.X>
24. Harrington KF, Zhang B, Magruder T, Bailey WC, Gerald LB. The impact of parent's health literacy on pediatric asthma outcomes. *Pediatric Allergy, Immunology, and Pulmonology*. 2015; 28(1): 20-26. <https://doi.org/10.1089/ped.2014.0379>
25. Berkman ND, DeWalt DA, Pignone MP, Sheridan SL, Lohr KN, Lux L, et al. Literacy and health outcomes: summary. *AHRQ Evidence Report Summaries*. Rockville (MD): Agency for Healthcare Research and Quality; 2004.
26. Sanders LM, Thompson VT, Wilkinson JD. Caregiver health literacy and the use of child health services. *Pediatrics*. 2007; 119(1): 86-92. <https://doi.org/10.1542/peds.2005-1738>
27. Van der Heide I, Rademakers J, Schipper M, Droomer M, Sørensen K, Uiters E. Health literacy of Dutch adults: a cross sectional survey. *BMC Public Health*. 2013; 27(13): 179. <https://doi.org/10.1186/1471-2458-13-179>
28. Toçi E, Burazeri G, Sørensen K, Kamberi H, Brand H. Concurrent validation of two key health literacy instruments in a South Eastern European population. *The European Journal of Public Health*. 2015; 25(3): 482-486. <https://doi.org/10.1093/eurpub/cku190>
29. Omachi TA, Sarkar U, Yelin EH, Blanc PD, Katz PP. Lower health literacy is associated with poorer health status and outcomes in chronic obstructive pulmonary disease. *Journal of General Internal Medicine*. 2013; 28: 74-81. <https://doi.org/10.1007/s11606-012-2177-3>
30. Scotten M. Parental health literacy and its impact on patient care. *Primary Care: Clinics in Office Practice*. 2015; 42(1): 1-16. <https://doi.org/10.1016/j.jpop.2014.09.009>
31. Adib-Hajbaghery M, Ahmadi B. Caregiver burden and its associated factors in caregivers of children and adolescents with chronic conditions. *International Journal of Community Based Nursing and Midwifery*. 2019; 7(4): 258-269.
32. Toledano-Toledano F, Domínguez-Guedea MT. Psychosocial factors related with caregiver burden among families of children with chronic conditions. *Bio Psycho Social Medicine*. 2019; 13(1): 1-9. <https://doi.org/10.1186/s13030-019-0147-2>
33. Piran P, Khademi Z, Tayarim N, Mansouri N. Caregiving burden of children with chronic diseases. *Electronic Physician*. 2017; 9(9): 5380-5387. <https://doi.org/10.19082/5380>
34. Türe E, Yazar A, Akın F, Aydın A. [Evaluation of caregiving burden in caregivers of children with chronic illness]. *Bozok Tıp Dergisi*. 2018; 8(03): 46-53 (in Turkish). <https://doi.org/10.16919/bozoktip.403880>
35. Doğan R, Yıldız E, Bağcı N. [The relationship between care burden and depression in liver transplant donors with a caregiver role]. *Adıyaman Üniversitesi Sağlık Bilimleri Dergisi*. 2021; 7(3): 277-285 (in Turkish). <https://doi.org/10.30569/adiyamansaglik.1003919>