Journal of Pediatric Nursing 48 (2019) e21–e26

Contents lists available at ScienceDirect

Journal of Pediatric Nursing

journal homepage: www.pediatricnursing.org

Evaluation of the Burden of Care and the Quality of Life in the Parents of Turkish Children with Familial Mediterranean Fever

Zahide Koşan, Sinan Yılmaz, Ezel Bilge Yerli *, Edanur Köyceğiz

Department of Public Health, Ataturk University Medical Faculty, Turkey

ARTICLE INFO

Article history:
Received 24 February 2019
Revised 27 May 2019
Accepted 27 May 2019

Keywords:
Familial Mediterranean fever
Family caregivers
Caregivers/psychology
Quality of life
Chronic disease/nursing
Children

ABSTRACT

Purpose: This study aimed to determine the burden of care and the quality of life in caregivers of children with FMF.
Design and methods: A cross-sectional study was conducted. Caregivers of the 109 children with FMF followed by a pediatric nephrology department were invited to join the study. Besides demographic information, the Zarit Care Burden Scale (ZCBS) and the World Health Organization Quality of Life Questionnaire-Short Form (WHOQOL-BREF) were used to collect data. Results for 90 patients were analyzed.
Results: The mean (±SD) ZCBS score of the caregivers was 44.78 ± 13.55. Care burden of the caregivers according to the ZCBS was categorized as; 61.1% ($n = 55$) mild, 25.6% ($n = 23$) moderate, and 13.3% ($n = 12$) severe. Although single caregivers were perceived as having a relatively higher burden than those who were married (80% and 36%), this difference was not significant. There were no statistically significant differences between ZCBS categories concerning caregivers' gender, educational status, and having comorbidities ($p > 0.05$). Also, there were no significant correlations between ZCBS and the WHOQOL-BREF domains ($p > 0.05$).
Conclusion: This study showed that the quality of life of the caregivers of children with FMF was not adversely affected, but a significant number of caregivers perceived care burden in moderate severity. Attention should be paid to the needs of caregivers, and they should be provided with adequate social, economic, physical, and psychological support.
Practice implication: Responsive strategies to support caregivers' should be taken as means of social, economic, physical, and psychological needs.

Introduction

Background/rationale

Familial Mediterranean fever (FMF) is a chronic inflammatory and autosomal recessive inherited disease with recurrent attacks, characterized by episodes of fever and inflammation of the serous membranes (Kosan, Cayir, & Turan, 2013; Kucuk, Gezer, Ucar, & Karahan, 2014). Although FMF prevalence shows geographical differences, still its reputation is "the most common inherited autoinflammatory disease" (Ciccarelli, De Martinis, & Ginaldi, 2014). The disease is prevalent among eastern Mediterranean populations, non-Ashkenazi Jews, Armenians, Turks, and Arabs, and is usually symptomatic during childhood or adolescence (Sari, Birlik, & Kasifoglu, 2014). Its prevalence in Turkey is approximately 1 per 1000 population (Tunca et al., 2005). A large study conducted by the Turkish FMF Study (Tunca et al., 2005) Group estimated that 70% of FMF cases were located in Central Anatolia, Middle Black Sea, and Eastern Anatolia.

Although the treatment with colchicine has dramatically changed the prognosis of FMF patients, decreasing the appearance of febrile attacks and preventing amyloidosis (Demirkaya, Erer, Ozen, & Ben-Chetrit, 2016), there is still a substantial burden on the caregivers (Ağkaya Alahan, Aylaz, & Yetiş, 2015; Press, Neumann, Abu-Shakra, Bolotin, & Buskila, 2000). Zarit and colleagues define the burden of care as: "The extent to which caregivers perceive that caregiving has had an adverse effect on their emotional, social, financial, physical, and spiritual functioning."(Zarit, Todd, & Zarit, 1986) This definition emphasizes that care is a multidimensional and highly individualized experience (Gillick, 2013). It brings many burdens to a family due to chronic diseases, symptoms, treatment methods, disease course, daily activity limitations, and long-term effects.

Several studies have shown that chronic diseases cause psychological and emotional distress, physical illness, family disintegration, disruption of social and sexual relations, a decrease in social activities, and economic difficulties in families (Abegunde, Mathers, Adam, Ortegon, & Strong, 2007; Fekih-Romdhane, Henchiri, Ridha, Labbane, & Cheour, 2018; Karahan & İslam, 2013; Toseland, Smith, & Mccallion, 2001). Thus, the quality of life of the caregivers may be heavily compromised (Press et al., 2000). On the other hand, although caregiving is at times stressful (e.g., the need for substantial assistance with activities

---

* Corresponding author at: Atatürk Üniversitesi, Tıp Fakültesi, Morfoloji binası, Halk Sağlığı Anabilim Dalı, Yakutiye, Erzurum, Turkey.
E-mail address: bilgeyerliezel@gmail.com (E. Bilge Yerli).

https://doi.org/10.1016/j.pedn.2019.05.017

of daily living, social isolation, and financial deprivation as a result of illness and caregiving), it can be emotionally rewarding because it can affirm family ties and save family resources (Tarlow et al., 2004).

Family caregivers are often neglected or overlooked as significant factors influencing patient care and outcomes. However, there is ever-growing evidence that the status of the family caregiver directly affects the patients. There are studies investigating the burden of care of caregiving family members in children with diabetes, liver failure, epilepsy, leukemia, and kidney failure (Ağkaya Alahan et al., 2015; Penovich, Buelow, Steinberg, Sirven, & Wheless, 2017). But the medical literature lacks any information on care burden and factors associated with family caregivers of children with FMF.

Objectives

This study aimed to determine the burden of care and the quality of life of family caregivers who had a child with FMF and to investigate the potentially related factors.

Methods

Study design

The study was conducted in a descriptive, cross-sectional plan. Study reporting was done per the STROBE guidelines (Von Elm et al., 2007). The study protocol was approved by the Local Ethics Committee Atatürk University Faculty of Medicine. Each participant signed an informed consent form in accordance with the Declaration of Helsinki.

Setting and participants

The research was done at Atatürk University Faculty of Medicine Hospital between December 2016 and June 2017. Erzurum province in eastern Turkey has a population of 750,000. Atatürk University Faculty of Medicine Hospital was established in 1962 as a regional hospital in Eastern Anatolia, Turkey. The participants of the study consisted of parents of children who were diagnosed with FMF and were followed regularly at the Atatürk University Medical Faculty Pediatric Nephrology Policlinic. 109 patients with FMF using oral colchicine were included in the study. An attempt was made to contact caregivers of all patients by phone and invite to join the study. Nine caregivers could not be contacted. Out of the contacted, eight rejected to join, and two were excluded due to insufficient/unreliable data provided during the interview. Results for 90 patients were analyzed (Fig. 1).

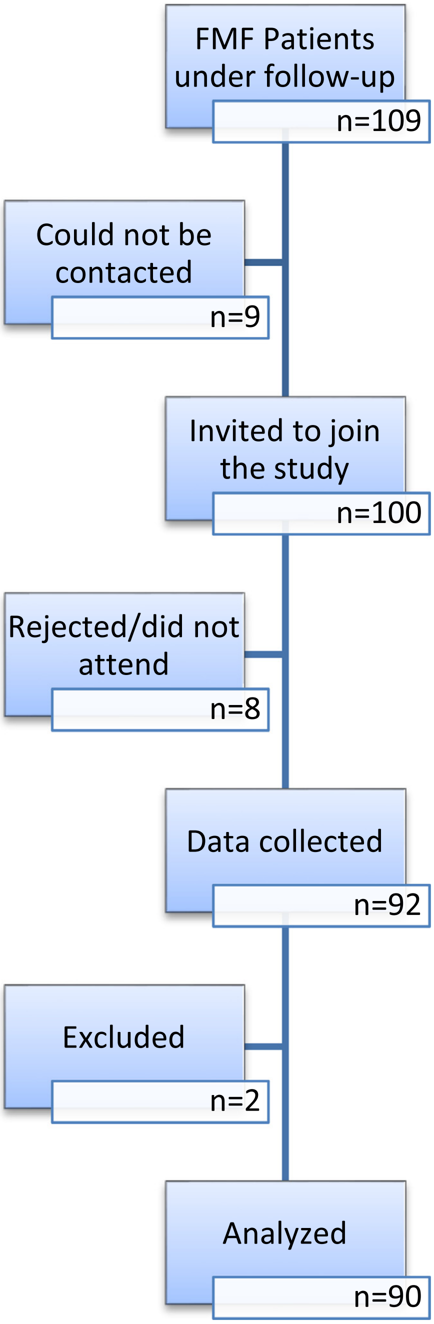

Fig. 1. Study flow chart.

Variables

The main outcome variable of the study was Zarit Caregiver Burden Scale (ZCBS) scores. The study data were collected after informed consent from volunteering parents, who brought their children for a follow-up to the pediatric nephrology, using face-to-face interview technique in an empty room at the outpatient clinics. A demographic information questionnaire consisting of 28 items was prepared by the researchers. Additionally, the ZCBS and the World Health Organization Quality of Life Questionnaire-Short Form Turkish Version (WHOQOL-BREF-TR) were used to collect data.

Data on the following variables were collected related to caregivers: ZCBS score, WHOQOL-BREF-TR score, age, gender, education, marital status, and presence of comorbidity. Data collection lasted approximately 45 min.

The variables collected about the cared patients with FMF were: Age, gender, education, the age at the diagnosis of FMF, duration of the treatment, number of attacks, frequency follow-up visits, number of siblings, order of birth, maternal age, father's age, parental education, father's occupation, mother's occupation, family type, family income level, residence, FMF among first or second degree relatives, FMF in the mother, FMF in the father, FMF in brother or sister, and FMF in other relatives.

The ZCBS was developed by Zarit et al. in 1980 (Zarit, Reever, & Bach-Peterson, 1980) and validated for Turkish by Özlü et al. (Özlü, Yıldız, & Aker, 2009). The Scale has been developed for evaluating the burden of caregivers of patients. The scale can be filled by the caregiver or the researcher and consists of 22 statements determining the effects of caregiving on the life of the individual. The items in the scale focus on mental and physical health, social and emotional experiences, economic situation, and interpersonal relationships. Item in the scale are rated as 1 = never, 2 = rarely, 3 = sometimes, 4 = quite frequently, and 5 = nearly always. The scare is interpreted as higher scores meaning more experienced burden (score: ≤21 = no burden; 22–46 = mild burden; 47–55 = moderate burden; ≥56 = severe burden) (Özlü et al., 2009).

The reliability analysis of the scale gave a Cronbach's α of 0.89 for this study.

The WHOQOL-BREF-TR is developed by the WHO (WHOQoL Group, 1996) and validated for Turkish by Eser et al. (Ser et al., 1999). The scale consists of 27 items that evaluate a person's quality of life and general health, measuring physical, mental, social, and environmental well-being. Scoring is done on a 4–20 scale with higher scores indicating a better quality of life (QoL).

Bias

In the questionnaire, there was brief information about the research to ensure that the research data were obtained correctly, and participants were asked not to put their identities on the questionnaire form. To prevent bias, error checking and debugging were done after the data was entered into the computer.

Study size

All primary caregivers of the patients under follow-up were invited to join the study; no sampling method was used.

Statistical methods

Data were analyzed using the SPSS 25.0 software. The results were presented as frequencies, percentages, mean (±SD), median (min-max) and interquartile range. For the comparison of the demographic data, the Chi-Square test was used for categorical variables. The distribution of the numerical variables was assessed by the Kolmogorov–Smirnov test. Associations between various numerical variables were investigated using Spearman's correlation analysis. A *p* value of <0.05 was considered as statistically significant.

Results

Participants

The study comprised 90 caregivers. The median (min-max) age of the caregivers was 40 (29–70) years. Of the participants, 63.3% ($n = 57$) were males, 68.9%, ($n = 62$) had primary education, 94.4% ($n = 85$) were married, and 35.6% ($n = 32$) had some comorbidities. Demographic variables of the caregivers are given Table 1.

The median (min-max) age and duration of treatment of FMF patients were 11 (1–19) years and 36 (0–192) months, respectively. Of the patients, 52.2% ($n = 47$) were females and 78.8% ($n = 71$) were students. 83.3% ($n = 75$) of the mothers were housewives. The majority of the patients (84.4%; $n = 76$) had a nuclear family, and 58.9% ($n = 53$) had FMF in the family. Demographic characteristics of the FMF patients are given Table 2.

Table 1
Demographic characteristics of the caregivers.

Variables		Median (min-max)/n	IQR/%
Age (year)		40 (29–70)	10.0
Gender	Female	33	36.7
	Male	57	63.3
Education	No formal education	2	2.2
	Primary school	62	68.9
	High School or equivalent	17	18.9
	University and above	9	10.0
Marital status	Single	5	5.6
	Married	85	94.4
Comorbidity	Yes	32	35.6
	No	58	64.4

SD: Standard deviation.

Table 2
Demographic characteristics of the Familial Mediterranean Fever patients.

Variables		Median (min-max)/n	IQR/%
Age (year)		11 (1–19)	114.0
Gender	Female	47	52.2
	Male	43	47.8
Education	Primary school	20	22.2
	Secondary school	25	27.8
	High school	26	28.9
	Not a student	19	21.1
Age at FMF diagnosis (months)		69 (4–204)	72.0
Duration of treatment (months)		36 (0–192)	60.0
Number of attacks per year		4.5 (0—120)	10.0
Frequency of follow-up per year		3.0 (0—12)	4.0
Number of siblings		3 (1—10)	2.0
Order of birth	1	30	33.3
	2	27	30.0
	3	14	15.6
	4	12	13.3
	≥5	7	7.7
Mother's age (years)		38.0 (27–56)	10.0
Father's age (years)		42.5 (33–71)	10.0
Mother's education	Illiterate/literate	13	14.4
	Primary education	43	47.8
	Secondary education	19	21.1
	High school	9	10.0
	University	6	6.7
Father's education	Illiterate/literate	2	2.2
	Primary education	22	24.4
	Secondary education	21	23.3
	High school	34	37.8
	University	11	12.2
Mother's occupation	Housewife	75	83.3
	Government employee	6	6.7
	Self-employed	4	4.4
	Other	5	5.6
Father's occupation	Government employee	15	16.7
	Self-employed	42	46.7
	Farmer	4	4.4
	Other	29	32.2
Family type	Nuclear family	76	84.4
	Extended family	14	15.6
Family income level	High	15	16.7
	Middle	72	80.0
	Low	3	3.3
Residence	Erzurum city center	42	46.7
	Erzurum district	15	16.7
	Other provincial centers	24	26.7
	Other districts	9	10.0
FMF in the family	Yes	53	58.9
	No	37	41.1
FMF in the mother	Yes	16	17.8
	No	74	82.2
FMF in the father	Yes	11	12.2
	No	79	87.8
FMF in the brother	Yes	22	24.4
	No	68	75.6
FMF in other relatives	Yes	20	22.2
	No	70	77.8

FMF: Familial Mediterranean fever, SD: Standard deviation.

Descriptive data

The mean (±SD) ZCBS score of the caregivers was 44.78 ± 13.55. Care burden of the caregivers according to the ZCBS was categorized as; 61.1% ($n = 55$) mild, 25.6% ($n = 23$) moderate and 13.3% ($n = 12$) severe (Fig. 2).

The mean (±SD) score of quality of life was 15.01 ± 2.59 in the "Physical domain," 14.93 ± 2.55 in the "Psychological domain," 15.04 ± 2.98 in the "Social Relationship domain," and 14.29 ± 2.24 in the "Environment domain."

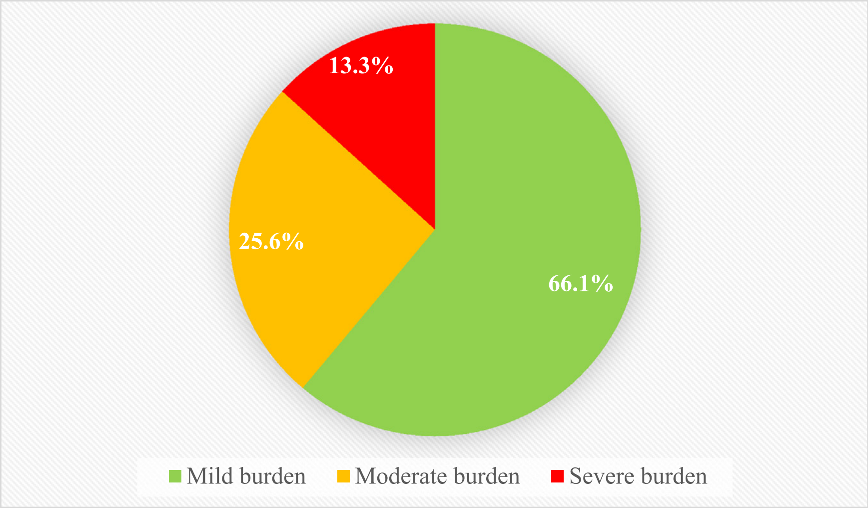

Fig. 2. Care burden of the caregivers according to the Zarit burden scale.

Outcome data

A moderate or severe burden of care was present in 80.0% ($n = 4$) of the single and 36% ($n = 31$) of the married caregivers, however there was no statistically significant difference between them. There were also no statistically significant differences between ZCBS categories concerning caregivers' gender, education, and the presence of comorbidities ($p > 0.05$) (Table 3).

There were no significant correlations between ZCBS and patients age, caregivers age, and WHOQOL-BREF-TR domains scores ($p > 0.05$). Associations between ZCBS scores and some patients and caregiver characteristics are given Table 4.

There were no statistically significant differences between ZCBS categories concerning patient characteristics ($p > 0.05$) (Table 5).

Discussion

The caregivers of FMF patients experience a substantial amount of care burden. According to the ZCBS scores, 38.9% of the caregivers had moderate or severe care burden. On the other hand, the quality of life scores of the caregivers were at levels around 15 on a scale of 4–20. Highest scores were observed in the physical domain, followed by psychological, social relationships, and the environment domains. Although the single caregivers perceived relatively higher burden compared to the married ones (80% vs. 36%), this difference was not significant. There were no statistically significant differences between ZCBS categories concerning caregivers' gender, educational status, and having comorbidities ($p > 0.05$). Also, there were no statistically significant correlations between ZCBS and the WHOQOL-BREF domains ($p > 0.05$).

In this study, nearly half of the caregivers experienced moderate to severe levels of care burden. The literature lacks comparative data for care burden in the caregivers of FMF patients. However, there are numerous studies investigating the caregiver burden in other chronic diseases. Many of these studies have employed the ZCBS as outcome measures, which allows making comparisons.

The results of a study among patients with renal failure indicated that caregivers of hemodialysis patients experienced relatively moderate levels of care burden (Jafari, Ebrahimi, Aghaei, & Khatony, 2018). Al-Balushi et al. investigated the overall burden among caregivers of drug-naive children and adolescents and reported that the prevalence of the burden of care was estimated at 34% (Al-Balushi et al., 2018). Li et al. reported that care burden among primary caregivers of adolescent scoliosis adolescent ZCBS was 36.83 ± 13.30, and most caregivers (88.5%) had moderate or severe burden (Li et al., 2018). A study conducted by Manzato Sadki et al. included family caregivers of young patients with chronic neurological diseases, and they reported that 65.5% of the caregivers felt little or no burden (Manzato Sadki et al., 2018).

The level of care burden experienced by caregivers can be influenced by many factors such as governmental and non-governmental support

Table 3
Distribution of Zarit caregiver burden according to participant characteristics.

Characteristics		Zarit caregiver burden					
		Mild		Moderate + Severe			
		n	%	n	%	χ^2	*p*
Gender	Female	21	63.6	12	36.4	0.140	0.708
	Male	34	59.6	23	40.4		
Education	None at all + primary	39	60.9	25	39.1	1.530	0.465
	High School or equivalent	9	52.9	8	47.1		
	University and above	7	77.8	2	22.2		
Marital status	Never married	1	20.0	4	80.0		0.073[a]
	Married	54	63.5	31	36.5		
Other diseases	Yes	18	56.3	14	43.8	0.494	0.482
	No	37	63.8	21	36.2		

[a] Fisher's Exact Test.

Table 4
Spearman correlations between ZCBS and some Familial Mediterranean Fever patients and caregiver characteristics.

Characteristics		Zarit caregiver burden scale score	
		Rho	*p*
Patients	Age (years)	−0.176	0.096
	Age at diagnosis (months)	−0.044	0.680
	Duration of treatment (months)	−0.003	0.980
	Mother's age (years)	−0.015	0.888
	Father's age (years)	0.159	0.134
	Number of attacks	0.239	0.023
	Number of siblings	0.087	0.414
	Frequency of follow-up	−0.186	0.079
Caregivers	Age (years)	0.075	0.481
	WHOQOL-BREF domains		
	Physical health	0.050	0.642
	Psychological	0.139	0.193
	Social relationships	0.066	0.539
	Environment	0.035	0.744

Table 5
Distribution of Zarit caregiver burden according to Familial Mediterranean Fever patient characteristics.

Characteristics		Zarit caregiver burden					
		Mild		Moderate + severe			
		n	%	n	%	χ^2	p
Gender	Female	31	66.0	16	34.0	0.972	0.324
	Male	24	55.8	19	44.2		
Education	Primary school	10	50.0	10	50.0	4.132	0.248
	Secondary school	14	56.0	11	44.0		
	High school	20	76.9	6	23.1		
	Not a student	11	57.9	8	42.1		
FMF in the family	Yes	32	60.4	21	39.6	0.029	0.864
	No	23	62.2	14	37.8		
FMF in the mother	Yes	11	68.8	5	31.3	0.478	0.489
	No	44	59.5	30	40.5		
FMF in the father	Yes	8	72.7	3	27.3		0.518[a]
	No	47	59.5	32	40.5		
FMF in the brother	Yes	15	68.2	7	31.8	0.613	0.434
	No	40	58.8	28	41.2		
Mother's education	Illiterate/literate	6	46.2	7	53.8	3.518	0.491
	Primary education	30	69.8	13	30.2		
	Secondary education	10	52.6	9	47.4		
	High school	5	55.6	4	44.4		
	University	4	66.7	2	33.3		
Father's education	Illiterate/literate	0	0.0	2	100.0	3.404	0.506
	Primary education	14	63.6	8	36.4		
	Secondary education	13	61.9	8	38.1		
	High school	20	58.8	14	41.2		
	University	8	72.7	3	27.3		
Mother's occupation	Housewife	44	58.7	31	41.3	1.647	0.656
	Government employee	5	83.3	1	16.7		
	Self-employed	3	75.0	1	25.0		
	Other	3	60.0	2	40.0		
Father's occupation	Government employee	8	53.3	7	46.7	2.906	0.429
	Self-employed	29	69.0	13	31.0		
	Farmer	3	75.0	1	25.0		
	Other	15	51.7	14	48.3		
Family type	Nuclear family	45	59.2	31	40.8	0.743	0.389
	Extended family	10	71.4	4	28.6		
	Separated family	0	0.0	0	0.0		
Household income	High	10	66.7	5	33.3	1.169	0.666[a]
	Middle	44	61.1	28	38.9		
	Low	1	33.3	2	66.7		
Residence	Erzurum city center	30	71.4	12	28.6	5.485	0.140
	Erzurum district	10	66.7	5	33.3		
	Other provincial centers	11	45.8	13	54.2		
	Another district	4	44.4	5	55.6		

[a] Fisher's Exact Test.

of caregivers and the dominant culture of the society. Caring reactions, coping strategies, and attitudes towards care are influenced by culture. Accordingly, cultural norms in eastern societies like Turkey make families responsible for the care of patients. Thus, the policymakers should focus on culture-specific formal caregiver services. On the other hand, we claim that doctors have a responsibility to recognize the caregiver burden and guide the individuals to the relevant resources. Caregiver assessment and intervention should be tailored to the individual circumstances and contexts in which caregiver burden occurs.

Quality of life (QoL) measurements are useful in assessing the general wellbeing of individuals. Although a negative correlation is expected between burden and QoL (Srivastava, Tripathi, Tiwari, Singh, & Tripathi, 2016), this could not be demonstrated in our study. The QoL of patients with rheumatic diseases is adversely affected to an extent comparable with that of other chronic diseases, such as chronic obstructive pulmonary diseases and insulin-dependent diabetes (Burckhardt, Clark, & Bennett, 1993). However, the impact of such diseases, specifically FMF, on the QOL of their relatives has not yet been studied. In our study, the caregivers' QoL was moderate. A study was conducted by Press et al. (Press et al., 2000) in parents living with a child with FMF, and they reported that the QoL and psychological well-being of parents with FMF children (especially that of the mothers) were slightly impaired. Tseng et al. reported that when compared with the general population, caregivers of children with cerebral palsy reported a significantly lower QoL in all domains except the environment domain (Tseng et al., 2016). Their quality of life was lower than what we found in our study.

Contrary to what was expected, in this study, no factors were affecting the care burden in caregivers and patients, except for marital status. We concluded that this difference might be related with the study population being children and the fact that only 13%of our population reported severe burden. Studies demonstrating a significant effect of caregiver age, gender, closeness to the patient, willingness to provide care, educational status, economic status, the presence of comorbidities, coping skills, beliefs, and social support on the perceived care burden are mostly conducted in adult patients (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014; Liu et al., 2017; Mosley, Moodie, & Dissanayaka, 2017).

Strengths and limitations

This is the first study to examine the burden of care in families who have children with FMF. Some limitations of this study can be mentioned as follows. First, the study sample is not community-based; it is hospital-based. Hence, our results can be generalized only to pediatric-age patients followed-up in tertiary centers. For this reason, there is no external validity of the results. Second, the data collection method, which was based on self-reporting, bears the limitations of questionnaire studies. Third, absence of a structured severity score in this study.

Implications for practice and future research

Children diagnosed with familial Mediterranean fever require chronic care management as there is no cure and its clinical course is unpredictable characterized by periods of acute exacerbations characterized by fever, pain and inflammation of the joints, abdomen and chest. Ongoing support and education is needed for parents not only to manage their children's care needs during acute periods of FMF exacerbations, but learn to seek and access resources to assist them with managing the burden of care as well as their own needs and those of family members. Responsive strategies to support caregivers' social, economic, physical, and psychological needs can support. can be of assistance in improving caregivers' quality of life.

Future studies are needed to enhance understanding of the relationship of the burden of care and quality of life of parents of children with familial Mediterranean fever with larger samples using longitudinal designs. Additionally, future studies are needed to explore the caregiver burden and quality of life in samples of families who are served in other regions in Turkey with different access to services.

Conclusion

In conclusion, this study showed that the quality of life of the caregivers of children with FMF was not adversely affected, but a significant number of caregivers perceived care burden in moderate severity. For this reason, attention should be paid to the needs of caregivers, and they should be provided by adequate social, economic, physical, and psychological support. As healthcare continues to evolve to largely outpatient and home-based care, family caregivers are emerging as one of the most essential members of the healthcare workforce. Efforts to understand their needs and provide training for their roles will benefit all, especially the patients depending on the care.

Funding

None.

Declaration of Competing Interest

None.

References

Abegunde, D. O., Mathers, C. D., Adam, T., Ortegon, M., & Strong, K. (2007). The burden and costs of chronic diseases in low-income and middle-income countries. *Lancet (London, England)*, *370*(9603), 1929–1938. https://doi.org/10.1016/S0140-6736(07)61696-1.

Adelman, R. D., Tmanova, L. L., Delgado, D., Dion, S., & Lachs, M. S. (2014). Caregiver burden: A clinical review. *JAMA*, *311*(10), 1052–1060https://doi.org/10.1001/jama.2014.304.

Ağkaya Alahan, N., Aylaz, R., & Yetiş, G. (2015). The burden of care in the parents of the children with chronic disease. *İnönü Üniversitesi Sağlık Bilimleri Dergisi*, *4*(2), 1–5.

Al-Balushi, N., Al-Alawi, M., Al Shekaili, M., Al-Balushi, M., Mirza, H., Al-Huseini, S., … Al-Adawi, S. (2018). Predictors of burden of care among caregivers of drug-naive children and adolescents with ADHD: A cross-sectional correlative study from Muscat, Oman. Journal of Attention Disorders, 1087054718808381. doi:https://doi.org/10.1177/1087054718808381.

Burckhardt, C. S., Clark, S. R., & Bennett, R. M. (1993). Fibromyalgia and quality of life: A comparative analysis. *Journal of Rheumatology*, *20*(3), 475–479.

Ciccarelli, F., De Martinis, M., & Ginaldi, L. (2014). An update on autoinflammatory diseases. *Current Medicinal Chemistry*, *21*(3), 261–269.

Demirkaya, E., Erer, B., Ozen, S., & Ben-Chetrit, E. (2016). Efficacy and safety of treatments in Familial Mediterranean fever: A systematic review. *Rheumatology International*. https://doi.org/10.1007/s00296-015-3408-9.

Fekih-Romdhane, F., Henchiri, H., Ridha, R., Labbane, R., & Cheour, M. (2018). Psychological distress and caregiving burden among spouses of women with breast cancer. *L'Encephale*. https://doi.org/10.1016/j.encep.2018.09.003.

Gillick, M. R. (2013). The critical role of caregivers in achieving patient-centered care. *JAMA: The Journal of the American Medical Association*. https://doi.org/10.1001/jama.2013.7310.

Jafari, H., Ebrahimi, A., Aghaei, A., & Khatony, A. (2018). The relationship between care burden and quality of life in caregivers of hemodialysis patients. *BMC Nephrology*, *19*(1), 321.

Karahan, A., & İslam, S. (2013). A comparative study on caregiver burden of caregivers to physically disabled, pediatric and geriatric patients. *MUSBED*, *3*(1), S1–S7.

Kosan, C., Cayir, A., & Turan, M. I. (2013). Relationship between genetic mutation variations and acute-phase reactants in the attack-free period of children diagnosed with familial Mediterranean fever. *Brazilian Journal of Medical and Biological Research = Revista Brasileira de Pesquisas Medicas e Biologicas*, *46*(10), 904–908. https://doi.org/10.1590/1414-431X20133178.

Kucuk, A., Gezer, I. A., Ucar, R., & Karahan, A. Y. (2014). Familial Mediterranean fever. *Acta Medica (Hradec Králové)*, *57*(3), 97–104. https://doi.org/10.14712/18059694.2014.47.

Li, C., Miao, J., Gao, X., Zheng, L., Su, X., Hui, H., & Hu, J. (2018). Factors associated with caregiver burden in primary caregivers of patients with adolescent scoliosis: A descriptive cross-sectional study. *Medical Science Monitor: International Medical Journal of Experimental and Clinical Research*, *24*, 6472–6479. https://doi.org/10.12659/MSM.909599.

Liu, S., Li, C., Shi, Z., Wang, X., Zhou, Y., Liu, S., & Ji, Y. (2017). Caregiver burden and prevalence of depression, anxiety and sleep disturbances in Alzheimer's disease caregivers in China. *Journal of Clinical Nursing*, *26*(9–10), 1291–1300. https://doi.org/10.1111/jocn.13601.

Manzato Sadki, E., Grabli, D., Flamand Roze, E., Baulac, M., Bourmaleau, J., & Lefebvre, S. (2018). Family caregivers of young patients suffering from chronic neurological diseases during the transition from neuropediatrics to adult neurology: An observational study of the burden felt by the primary family caregiver. *Recherche en Soins Infirmiers*, *133*, 93–98. https://doi.org/10.3917/rsi.133.0093.

Mosley, P. E., Moodie, R., & Dissanayaka, N. (2017). Caregiver burden in Parkinson disease: A critical review of recent literature. *Journal of Geriatric Psychiatry and Neurology*, *30*(5), 235–252. https://doi.org/10.1177/0891988717720302.

Özlü, A., Yıldız, M., & Aker, T. (2009). A reliability and validity study on the Zarit caregiver burden scale. *Archives of Neuropsychiatry*, *46*(Supp), 38–42.

Penovich, P. E., Buelow, J., Steinberg, K., Sirven, J., & Wheless, J. (2017). Burden of seizure clusters on patients with epilepsy and caregivers: Survey of patient, caregiver, and clinician perspectives. *The Neurologist*, *22*(6), 207–214. https://doi.org/10.1097/NRL.0000000000000140.

Press, J., Neumann, L., Abu-Shakra, M., Bolotin, A., & Buskila, D. (2000). Living with a child with familial Mediterranean fever: Does it affect the quality of life of the parents? *Clinical and Experimental Rheumatology*, *18*(1), 103–106.

Sari, I., Birlik, M., & Kasifoglu, T. (2014). Familial Mediterranean fever: An updated review. *European Journal of Rheumatology*, *1*(1), 21–33. https://doi.org/10.5152/eurjrheum.2014.006.

Ser, E., Fidaner, H., Fidaner, C., Yalçin, E., Elbi, H., & Göker, E. (1999). Psychometric properties of tlte WHOQOL-100 and WHOOOLBREF. *3P (Psikiyatri Psikol Psikofarmakoloji) Derg*, *7*(2), 23–40.

Srivastava, G., Tripathi, R. K., Tiwari, S. C., Singh, B., & Tripathi, S. M. (2016). Caregiver burden and quality of life of key caregivers of patients with dementia. *Indian Journal of Psychological Medicine*, *38*(2), 133–136. https://doi.org/10.4103/0253-7176.178779.

Tarlow, B. J., Wisniewski, S. R., Belle, S. H., Rubert, M., Ory, M. G., & Gallagher-Thompson, D. (2004). Positive aspects of caregiving: Contributions of the REACH project to the development of new measures for Alzheimer's caregiving. *Research on Aging*. https://doi.org/10.1177/0164027504264493.

Toseland, R., Smith, G., & Mccallion, P. (2001). Family caregivers of the frail elderly, handbook of social work practice with vulnerable and resilient populations. In A. Gitterman (Ed.), *Handbook of social work practice with vulnerable and resilient populations* (2nd ed.). New York: Columbia University.

Tseng, M. -H., Chen, K. -L., Shieh, J. -Y., Lu, L., Huang, C. -Y., & Simeonsson, R. J. (2016). Child characteristics, caregiver characteristics, and environmental factors affecting the quality of life of caregivers of children with cerebral palsy. *Disability and Rehabilitation*, *38*(24), 2374–2382. https://doi.org/10.3109/09638288.2015.1129451.

Tunca, M., Ozdogan, H., Kasapcopur, O., Yalcinkaya, F., Ozen, S., Topaloglu, R., ... Cobankara, V. (2005). Familial Mediterranean fever (FMF) in Turkey: Results of a nationwide multicenter study. *Medicine*. https://doi.org/10.1097/01.md.0000152370.84628.0c.

Von Elm, E., Altman, D. G., Egger, M., Pocock, S. J., Gøtzsche, P. C., & Vandenbroucke, J. P. (2007). The strengthening the reporting of observational studies in epidemiology (STROBE) statement: Guidelines for reporting observational studies. *PLoS Medicine*, *4*(10), 1623–1627. https://doi.org/10.1371/journal.pmed.0040296.

WHOQoL Group (1996). *WHOQoL-Bref: Introduction, administration, scoring, and generic version of the assessment.*

Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *The Gerontologist*, *20*(6), 649–655.

Zarit, S. H., Todd, P. A., & Zarit, J. M. (1986). Subjective burden of husbands and wives as caregivers: A longitudinal study. *The Gerontologist*, *26*(3), 260–266.