



The Caregiving Burden and Perception of Quality of Life of Caregivers of Technology Dependent Children with Chronic Disease and Disabilities: A View from One Center

Teknolojik Desteğe Bağımlı Yaşayan Kronik Hastalık ve Sakatlıkları Olan Çocukların Bakım Verenlerinin Yükü ve Hayat Kaliteleri: Bir Merkezden Görünüm

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Abstract

Introduction: Children with chronic diseases and disabilities those need support of medical technologies (TD) for living, have led to a load of complex nursing care being carried out usually by parents at their home. This study was carried out to evaluate the caregiving burden and perception of the quality of life of the caregivers of technology dependent children followed in our center.

Methods: A retrospective survey-based observational study carried out with primary caregivers of the TD children with chronic disease. Zarit burden scale (ZBS) and Turkish version of the SF-36 quality of life scale were used.

Results: Most of the primary caregivers were mothers (61%) or fathers of the TD children. 62% of the participants had been caring for these children for more than 3 years, and 75% of them cannot benefit from institutional home nursing services. More than half of the caregivers reported not having enough income to make ends meet, and about half of them stated to have to quit own jobs. It was seen that 74% of caregivers had at least one chronic disease, 32% of them had psychological problems under treatment. The mean score of caregivers' burden in total measured by ZBS was 52.8±14.3 points that indicating moderate load. Caregivers' burden showed a high strenght of positive correlation with ZF1 and ZF2 sub dimensions. Caregivers' increasing age, female gender, low income level, presence of chronic health problems of caregivers showed a significance in ZF1sub dimension. Quality of life scores of caregivers were found below than averages of Turkey in all 8 sub-categories (p<0.05). As the mean caregiver burden increased, quality of life scores of caregivers in all 8 categories decreased.

Öz

Giriş: Kronik hastalığı ve engeli olan, yaşamak için tıbbi teknolojilerin desteğine (TD) ihtiyaç duyan çocukların evde yürütülen karmaşık hemşirelik bakımı, genellikle ebeveynlerin üzerinde olan bakım yüküne yol açmıştır. Bu çalışma, merkezimizde izlenen teknolojik desteğe bağımlı çocukların bakım verenlerinin bakım verme yüklerini ve yaşam kalitesi algılarını değerlendirmek amacıyla yapılmıştır.

Yöntemler: Kronik hastalığı olan TD çocuklarına birincil bakım verenleri ile gerçekleştirilen ankete dayalı geriye dönük, gözlemsel bir çalışma yürütüldü. Zarit yük ölçeği (ZBS) ve SF-36 yaşam kalitesi ölçeğinin Türkçe versiyonu kullanıldı.

Bulgular: Birincil bakım verenlerin çoğu, TD'li çocukların anneleri (%61) veya babalarıydı. Katılımcıların %62'si bu çocuklara 3 yıldan fazla süredir bakmaktaydı ve %75'i kurumsal evde bakım hizmetlerinden yararlanamamaktaydı. Bakıcıların yarısından fazlası geçimlerini sağlamak için yeterli gelire sahip olmadığını ve yaklaşık yarısı bakım vermek için kendi işini bırakmak zorunda kaldığını belirtti. Bakım verenlerin %74'ünün en az bir kronik hastalığı olduğu, %32'sinin tedavi altında psikolojik sorun yaşadığı görüldü. ZBS ile ölçülen toplam bakım yükü puan ortalaması 52,8±14,3 puan olup orta düzeyde yüke işaret etmektedir. Bakım verenlerin yükü, ZF1 ve ZF2 alt ölçek boyutları ile yüksek güçlü bir pozitif korelasyon gösteriyordu. ZF3 ve ZF4 alt ölçek boyutları ile orta düzeyde pozitif korelasyon gösteriyordu (p<0,05). Bakım verenlerin artan yaşı, kadın cinsiyetinde oluşu, düşük gelir düzeyi, kronik sağlık sorunlarının varlığı ZF1 alt boyutunda anlamlı fark yaratıyordu. Bakım verenlerin yaşam kalitesi puanları 8 alt kategoride de Türkiye ortalamasının altında bulundu (p<0,05). Ortalama bakım verme yükü arttıkça, 8 kategorinin tamamında bakım verenlerin yaşam kalitesi puanları azalıyordu.

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Conclusion: This may contribute to medical and institutional professionals to develop targeted strategies to support these childrens' caregivers.

Keywords: Children with disabilities, home nursing, life support care, palliative care, biomedical technology, caregiver burden, quality of life, Zarith burden scale, SF-36 quality of life scale

Sonuç: Bu yerel ve küçük ölçekli çalışma sonuçları, medikal ve kurumsal profesyoneller tarafından bu çocukların bakım verenlerinin tanımlanmasına ve desteklenmesine yönelik hedefli stratejiler geliştirilmesine ve aile düzenlerinin sürdürülmesine katkıda bulunabilir.

Anahtar Kelimeler: Engelli çocuklar, evde hemşirelik, yaşam destek bakımı, palyatif bakım, biyomedikal teknoloji, bakım veren yükü, yaşam kalitesi, Zarith yük ölçeği, SF-36 yaşam kalitesi ölçeği

Introduction

The term "technology-dependent" (TD) is widely used to describe children; who need both a medical device to compensate for the loss of a vital body function, and substantial and ongoing nursing care to avert death or further disability.¹ In a report from UK on hospital discharge situations of technology dependent children was pointed that 41% of all hospital discharges were deemed to be technology dependent.² In one of our recent studies, we surveyed technology dependent children that have been following up at 14 centers of all over Turkey. The most reasons of technological dependency were congenital neuromuscular disease (30.6%), cerebral palsy and hypoxic ischemic encephalopathy (24.2%) and inborn errors of methabolism (17.7%) respectively. We revealed that 60% of them were dependent upon mechanical ventilation with tracheostomy, 47.9% of them dependent upon nutritional support with nasogastric tube and 37.9% of them dependent upon gastrostomy.³ Children with chronic diseases and disabilities of congenital or acquired problems those need support of medical technologies for living, have led to load of complex nursing care being carried out usually by parents at their home. It was reported that long-term caregiving at chronic illnesses and at end of life situations of adults has a dramatic impact on the health and well-being of family caregivers.^{4,7} However, there has been relatively less information on caregiving burden and quality of life of the family members as caregivers for their TD children in literature. Till to day could not found any study from Turkey that specifically examined this group.⁸⁻¹²

Purpose

Present study was carried out to evaluate the caregiving burden and perception of quality of life of caregivers of technology dependent children with chronic disease those followed in our hospital.

Materials and Methods

A retrospective survey-based observational study carried out between June and December 2017. During hospital admission and hospitalization of children, the purpose of

the study and how to do it has been explained to caregivers. After written informed consent was obtained and caregivers were assured of confidentiality, they were requested to fill in the questionnaire. In addition, the families of the patients reached by phone from the hospital records were invited for survey. Primary caregivers of the TD children with chronic disease aged under 18 years, who are at least literate, able to read, understand and fill in the questionnaire and volunteer to participate in the study were included the study. Sample size was determined according to the sample calculation nomogram developed for retrospective studies. Three of 103 people who did not agree to participate were excluded from the study.

Zarit burden scale (ZBS) were used for evaluation of caregiving burden.¹³ Caregivers asked to indicate to extent of burden experienced while providing care to their TD children. Burden is defined as the extent to which a caregiver perceives emotional, physical, health, social life and financial consequences that impair one's ability to provide care. It is a scale based on 22 questions that answer the objective and subjective burdens of the individual and are answered with 5-step option that range from "not at all" to "extremely". Total scores are obtained by summing all items endorsed. The total scoring range is between 22-110 points. It is defined as "light load" between 22-46 points, as "moderate load" between 47-55 points, and as "heavy load" between 56-110 points. Zarit consists of four sub-categories as; Zarit factor 1 (ZF1) (general assessment of physical, mental and social health, personal assessment of the economic situation), Zarit factor 2 (ZF2) (evaluation of social relations), Zarit factor 3 (ZF3) (evaluation of personal anxiety and satisfaction on the adequacy of the care provided), Zarit factor 4 (ZF4) (assessment of emotional load and tension). ZBS has been found to be practical and validated in the Turkish population by various studies such as in caregivers of elders and caregivers of patients with psychiatric disorders.^{14,15} Cronbach's alpha reliability test was performed to determine the reliability level of the Zarit caregiver burden scale. Cronbach's alpha reliability coefficient with standardized substances was 0.875 in this study, indicating adequate internal consistency (>0.70 acceptable internal consistency).

Cronbach's alpha reliability statistics of Zarit caregiver burden scale and subdimensions					
	Chronbach's alpha	Number of items	Overall mean of dimension	Between items	Hotellings
Zarit total	0.870	17	2.40	0.000	0.000
ZF1	0.800	7	2.50	0.000	0.000
ZF2	0.752	4	2.25	0.001	0.004
ZF3	0.719	3	2.65	0.000	0.000
ZF4	0.536	3	2.15	0.000	0.000

Caregivers' perception of quality of life were evaluated by using Turkish version of the SF-36 quality of life Scale, an established questionnaire for health related quality of life (QoL) assessment. There are 36 questions in the scale, and consists of eight subscales covering physical and mental components, role restriction due to physical and emotional problems, social function, mental health, energy and vitality, pain, general perception of health. The score of each sub-scale ranges from 0-100 points. Points and quality of life are directly proportional. SF-36 quality of life scale scores calculated by the score calculation method, which belongs to Turkey itself, were compared with the overall average scores of Turkey.^{16,17} In addition, a 25-questions general evaluation form was used to determine the demographical and social characteristics of the participants.

Statistical Analysis

In the statistical evaluation, according to the characteristics of the variables, Mann-Whitney U and X² tests, and bivariate and multivariate correlation tests were used. Significance accepted as p<0.05.

Approval to conduct the study was obtained from Local Clinical Research Ethics Committees of Akdeniz University (09.22.2017- 70904504/329).

Results

A convenience sample of 103 caregivers of technology dependent children with chronic illness those followed in our hospital was invited to participate. Most of the 100 included primary caregivers who agree to participate in the study, were middle aged females. 94% of participants were mothers (61%) or fathers of the TD children. Caregivers of TD children were mostly moderately educated (83%) and living in urban. More than half of participant reported not having enough income to make ends meet, and about one third of caregivers were employed full or part-time outside the home. It was seen that 74% of caregivers had at least one chronic disease, 32% of those had psychological problems under treatment such as depression (22 person), anxiety disorder (9 person) and obsessive-compulsive disorder (1 person). Details of caregivers' socio-demographical features are shown in Table 1.

62% of the participants had been caring for these children for more than 3 years. More than two-thirds of caregivers spent ≥3 hours a day and ≥30 hours a week to care, and 42% of caregivers had to quit their jobs for caring the children. More than half of the participants did not receive assistance from other members of the family while providing care, and only 2% of them had a paid caretaker. Table 2 shows the characteristics of caregivers related to caregive.

Features of caregivers' perception of quality of life and caregiving burden, and correlation between them, are given in Table 3.

Discussion

Cronbach's alpha for the ZBS with both full scale and deleted items were 0.875 and 0.800 respectively, pointing out an adequate internal consistency. The mean score of caregivers' burden measured by ZBS was 52.8±14.3 points that indicating moderate load.

In another study from Turkey, caregiving burden of the vast majority of parents of children with peritoneal dialysis evaluated by ZBS, has been reported to be moderate to high.¹² Similarly, studies from different countries, indicated that the burden of care shouldered by parents of children with special health care needs and chronic diseases was considerable.^{8,18,19} Caregivers' burden showed a high strenght of positive correlation with ZF1 sub dimension that covers caregiver's perception of own physical health, mental and social well-being and economic status, and with its evaluation of social relations (ZF2 sub dimension). Also caregivers' burden was moderately positive correlated with ZF3 and ZF4 sub dimensions. These findings are consistent with those of other studies from different parts of the world.²⁰ A report from United States of America, of a 5-month longitudinal study in monthly face-to-face interviews with caregivers, mostly mothers, revealed that the vast majority of them were feeling tired and weak even when they wake up, and frustrated, anxious, angry, helpless or hopeless and, were not having time and energy for social activities.⁸ And another study from middle-east region showed that caregivers had high to moderate scores of general strain, disappointment, isolation, emotional involvement and environment sub dimensions respectively.¹⁸ As in many reports

Table 1. Demographical features of caregivers (n=100)				
Characteristics		%	p*	r**
Age (year)	<25	5	0.003 (ZF1)	0.335
	26-45	65		
	>46	10		
Gender	Female	63	0.012 (ZF1)	-0.251 (ZF1)
	Male	37		
Resident place	Urban	71		ns
	Rural	29		
Education status	Primary	50	>0.05	0.204 (ZF2)
	High school	33		
	University	17		
Social security	Yes	87	0.029 (ZF3)	-0.290 (ZF3)
	No	13		
Employment status	Employed	36		0.198 (ZF1)
	Unemployed	64		
Income level by self assessment	Low	52	0.007 (ZF1)	-0.223
	Middle-high	48		
Chronic health problem	Yes	74	0.002 (ZF1)	-0.226
	No	26		
Habits	Yes	37		ns
	No	63		
Number of children	Non	2		0.332 (ZF1)
	1-2	63		
	3-4	35		

*p significance of difference in caregiver burden
**r correlation with caregiver burden, ZF: Zarit factor

Table 2. Characteristics of caregivers related with caregiving (n=100)				
Characteristics		%	p*	r**
How many years has she/he been caring?	<1	12	0.015	0.215 (ZF1)
	1-3	26		
	>3	62		
How many hours in a day does caregiving take?	<1	19	0.000 (ZF1)	0.293
	1-3	17		
	>3	64		
How many hours in a week does caregiving take?	<10	20		0.291
	10-30	15		
	>30	65		
Does family members help the caregiver for caring?	Yes	45	>0.05	ns
	No	55		
Does the caregiver be paid a salary by the government?	Yes	45	0.001 (ZF1)	-0.222
	No	55		
Has the caregiver been working before?	Yes	56	0.013 (ZF1)	-0.203 (ZF4)
	No	44		
Did the caregiver have to quit his/her job?	Yes	42	0.017 (ZF1)	-0.223
	No	28		
Have you employed a paid caretaker?	Yes	2		ns
	No	98		
Do you get support of the instutional home nursing services?	Yes	25	0.007 (ZF4)	-0.254
	No	75		
Would you like a caregiver support from the instutional home nursing services at your home?	Yes	48	0.003	-0.479
	No	52		

*p significance of difference in caregiver burden
**r correlation with caregiver burden, ZF: Zarit factor

Table 3. Features of caregivers' perception of quality of life and caregiving burden

	Score (mean ± SD)	Cronbach α R.C		
Zarit total	52.8±14.3	0.875		
	r *			p*
Zarit factor 1	0.877	0.80		0.000
Zarit factor 2	0.708	0.75		0.000
Zarit factor 3	0.386	0.71		0.000
Zarit factor 4	0.644	0.53		0.000
SF-36 QoL subcategories	r **	Score (mean ± SD)	Average score in Turkey (mean ± SD)	p**
Physical functioning	-0.298	75.8±26.2	86.6±25.2	0.003
Role-physical	-0.400	55±46.1	89.5±29.6	0.000
Social functioning	-0.381	68.1±29.8	94.8±14.4	0.000
Role-emotional	-0.294	63±41.5	94.7±20.9	0.003
Mental health	-0.410	70±17.7	73.5±11.6	0.000
Energy and vitality	-0.463	54.3±23.7	67±13.8	0.000
Bodily pain	-0.402	75.5±25	86.1±20.6	0.000
General health	-0.410	68.9±20.5	73.9±17.5	0.000

*p significance of difference in Zarit factors on caregiver burden
 **p significance of difference in scores of SF-36 QoL subcategories between average of Turkey and study group
 *r correlation of Zarit factors with caregiver burden
 **r correlation of scores of SF-36 QoL subcategories with caregiver burden
 QoL: Quality of life, SD: Standard deviation

had been stated, in present study caregivers' increasing age, female gender, low income level, presence of chronic health problems of caregivers showed a significance in ZF1sub dimension.^{8,18} Significant moderate strength of correlation was found between ZF1 subdimension and increasing number of children owned by caregivers. Length of time performing the role of caregiver showed a significant difference in caregivers' burden (p=0.015), as shown in literature.⁸ The ZF1sub-dimension scores of caregivers were significantly higher in those who had longer daily hours devoted to caregiving, and those who received payment for care from the state, worked before and had to leave the job (p<0.005). It could be said that the burden of care, especially in the physical sense, is mostly on the mothers' shoulders whose have other household responsibilities as well. Beside these, absence of social security made a significant difference in ZF3 sub dimension covering that caregivers' personal anxiety, and satisfaction with a sense of competence of caregiving. Caregivers those who cannot get help from state home care services had significantly higher scores of ZF4 subdimension signify emotional load and tension (p=0.007). The fact that more than thirty percent of caregivers have psychological problems under treatment can be considered as another sign of the emotional burden of caregiving. These findings are consistent with those of other studies.^{8,21-25} Quality of life scores of caregivers were found to be lower than averages of Turkey in all 8 sub-categories (p<0.05).¹⁶ These especially in physical and emotional role restriction and social function subcategories were remarkable.

As caregivers' burden related to caregiving increased, the quality of life scores of caregivers in all 8 categories decreased. The correlations between ZBS and QoL score subcategories of vitality and energy sensation, mental health, general perception of health, pain, and physical role restriction were most pronounced. These findings are consistent with prior studies from Turkey and the other countries of world.^{7,8,19}

Conclusion

It can be said that ZBS is a reliable and valid tool with an acceptable Chronbach alpha for measuring of caregiving burden in caregivers of TD children with chronic illness. The average burden of caregivers' was indicating a moderate load. It's revealed an another remarkable point that, 75% of caregivers' in our study population cannot benefit from institutional home nursing services. The increase in the burden of caregiving reduces the caregiver's quality of life in every sense. This local and small scale study may contribute to pave the way for medical and institutional professionals to identify and develop targeted strategies to support these childrens' caregivers and maintenance of their families. Within certain limits of the present study results, arrangements of health care programs to train skilled caregivers, education on coping strategies for different medical conditions, practical accessible home care support services, and psychological counselling services are recommended.

Ethics

Ethics Committee Approval: Approval to conduct the study was obtained from Local Clinical Research Ethics Committees of Akdeniz University (09.22.2017- 70904504/329).

Informed Consent: Written informed consent was obtained.

Peer-review: Externally peer-reviewed.

Authorship Contributions

Surgical and Medical Practices: N.E., M.A., A.K., Concept: N.E., M.A., A.K., Design: N.E., M.A., Data Collection or Processing: A.K., Analysis or Interpretation: N.E., M.A., Literature Search: N.E., A.K., Writing: N.E.

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