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The correlation between self-efficacy, care burden, and hopelessness of mothers with medical technology-dependent children

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Keywords: technology-dependent child, mother, self-efficacy, care burden, hopelessness

ABSTRACT

Background. Having a child dependent on medical technology devices might cause some challenges for parents. Identifying these challenges and producing solutions may significantly contribute to the home care provider. This study aims to examine the correlation between self-efficacy, care burden, and hopelessness of mothers with medical technology-dependent children.

Material and methods. This study was conducted using a cross-sectional and correlational design. Between April and July 2023, 164 mothers had at least one child receiving home care and were dependent on a medical technological device. The data were collected using an information form, the general self-efficacy scale, the Burden Scale for Family Caregivers, and the Beck Hopelessness Inventory.

Results. It was found that the self-efficacy of mothers with a child dependent on a medical technological device was on the mean, their care burden was above the mean, and their hopelessness was below the mean. As the mothers' self-efficacy increased, their hopelessness and care burden decreased. It was found that the mothers' self-efficacy significantly predicted their care burden and hopelessness.

Conclusions. In the hospital setting, it is necessary to initiate training, counselling, and psychosocial support for the caregivers and the entire family. Pediatric intensive care nurses play a significant role in achieving this.

Introduction

In recent years, the survival rate of children has been rising despite prematurity, congenital diseases, asphyxia, and acute or chronic health problems [1,2]. However, this brings a new perspective on the child's health problems, and the child may require lifelong treatment/care and supervision. After undergoing prolonged treatment and care services in intensive care units, they still have ongoing requirements when they are back in the comfort of their own homes [3,4].

An atmosphere similar to home that of a hospital setting is prepared, and necessary care for the child continues at home alongside their family. These children may depend on one or more medical technological devices, either temporary or permanent. These devices include a mechanical ventilator, an oxygen condenser, hemodialysis, peritoneal dialysis, or a feeding pump [5,6]. Even though it is known that the utilisation of these devices is not particularly widespread, the number of children dependent on medical devices at home is rising each day [7]. It is estimated that 6.3–6.6 children out of every 100.000 suffer from this problem among children under the age of 16. A study conducted in the United States of America between 2009 and 2010 estimated that the rate of children dependent on medical technology and having multiple chronic diseases is approximately 11 million, with a rate of 15% [3]. An estimated 600,000 children in the United States are technology-dependent and live at home, and this population continues to grow [8].

Even though medical technological devices improve the quality of life, home care is still the leading cause of high mortality and morbidity among children [9,10]. Moreover, shifting from a hospital to home care may exceed children's and their families' standards. The families also have significant responsibilities to ensure that the treatment and care services of the child are continued [11–13]. The family needs to know how to use all the devices the child is dependent on, what to do in case of emergency response, how to respond and when to notify the emergency team. The caregivers are known to be provided with the necessary verbal and practical training before discharge from the hospital [6,14]. Given that their parents are not members of the medical team, have no medical training, and have differences in their educational, economic, and cognitive abilities, it may be challenging to meet these children's treatment and care needs in their home setting [6,10,15,16].

Parents and other healthy children might be affected in terms of the processes in the family as well as its psychological, economic, and social qualities [8,14,17]. Stress, isolation, psychosocial problems and deterioration of family relationships cause the majority of these effects. It has been reported that care burdens parents of technology-dependent children [18], leads to difficulty in adapting to care and experiences stress and depression [2]. Parents must leave their jobs to care for their children, affecting the family's economy [15,19]. Studies have reported that families feel anxious while following up on their children and have little or no sleep while monitoring, leading to their psychological disorders [8,19,20]. The study by Nishigaki et al. reported that mothers experienced social and physiological difficulties, future anxiety, and psychological disorders since caring for their children lasted for 24 hours [13]. In the literature review, the inadequacy of identifying the needs of the child and the family during the home care of children dependent on medical technological devices and the insufficiency of presenting solution proposals are remarkable.

Additionally, information was not found regarding the social support provided to children dependent on medical technology in Turkey. The necessity for a holistic, humanistic, systemic, and political approach to children who require home treatment/care and their families, the number of whom is growing worldwide, is well known. Identifying the difficulties faced by the families of medical technology-dependent children may be necessary in drawing the boundaries of these approaches. Therefore, this study examined the correlation between mothers' self-efficacy, care burden and hopelessness with medical technology-dependent children.

Materials and Methods

Design of the study

This cross-sectional and correlational study.

Data collection

The study was conducted with parents with at least one child receiving home care and dependent on a medical technological device between April and July 2023. Although the study population was not identified due to insufficient prevalence studies in the country, the G*Power (3.7.9.1) program was used for the sample size. The program determined the sample size was 128 individuals with an effect size of 0.3, a sampling error of 0.05, and a confidence interval of 95%. Still, the study was completed with 164 mothers, considering the missing data.

Participants and setting

It was determined that the income of the parents who could be reached was provided by the father, and the primary caregiver of the child at home was the mother. Therefore, the sample size consisted of mothers. It was conducted with mothers who have a child dependent on medical technology and live within the borders of Turkey. The inclusion criteria were determined as having a child dependent on a medical technological device, physical and mental growth retardation in the child (total dependence on the parent), and providing care for the child at home. Mothers having children who were physically, cognitively, and socially semi-dependent were excluded from the study.

Data collection tools

The Information Form, prepared by the researcher following the literature review, contains 12 questions about the socio-demographic characteristics of children and their parents [5,20].

Burden Scale for Family Caregivers (BSFC): Sarı and Başbakkal developed the scale in 2008. It is a five-point Likert-type assessment tool comprising six subscales and 43 items. Its subscales are economic burden (1, 2, 3, 4, 5, and 6), physical burden (21, 22, 23, 24, and 25), emotional burden (26, 27, 28, 29, 30, 31, 32, 33, 34, 35, and 36), social burden (15, 16, 17, 18, 19, and 20), the perception of inadequacy (7, 8, 9, 10, 11, 12, 13, and 14), and time requirement (37, 38, 39, 40, 41, 42, and 43). The responses are scored by anchoring at "1=never, 2=rarely, 3=sometimes, 4=often-frequent, and 5=always". High scores signify that the family burden is high [21]. The cut-off point is 97. The reliability coefficient of Cronbach's alpha of the scale was 93. This value was 92 in the present study.

General Self-Efficacy Scale (GSE): The original scale developed by Sherer et al. consists of 23 items. It has a structure with two factors: General Self-Efficacy (explained variance of 26.5%, Cronbach's alpha = 0.86) and Social Self-Efficacy (explained variance of 8.5%, Cronbach's alpha = 0.71). Since the items in the first factor did not point to a specific behavioural domain, the title of "General Self-Efficacy" was deemed appropriate for this factor. The factor of Social Self-efficacy reflects the expectations of competence in social circumstances. The later version of the scale, initially a 14-point scale, was converted into a five-point Likert-type scale (Sherer and Adams 1983). Yıldırım and İlhan conducted the Turkish validity and reliability study of the scale. This is a five-point Likert-type scale consisting of a total of 17 items. Each item is rated from 1 (not at all) to 5 (very good), and the total score on the scale ranges between 17 and 85 points. Items 2, 4, 5, 6, 7, 10, 11, 12, 14, 16 and 17 are reversely scored. A higher score indicates an improvement in self-efficacy belief [22]. The Cronbach's alpha reliability coefficient of the scale is reported to be.80. In this study, this value was found to be 79.

Beck Hopelessness Scale (BHS): This scale was developed by Beck et al. in 1974 to determine pessimism about the future. It consists of 20 items and is scored between 0–1. The scale applies to both adults and adolescents. The scale is scored as follows: the "no" response for items 1, 3, 5, 6, 8, 10, 13, 15 and 19 gets 1 point, and the "yes" response for items 2, 4, 7, 9, 11, 12, 14, 16, 17, 18 and 20 gets 1 point. The high score signifies that the individual has a high level of hopelessness. Cronbach's alpha reliability coefficient of the scale is.85, Which was found to be.83 in this study.

Data Analysis

The Shapiro-Wilk test tested the normality distribution of continuous variables. With the Shapiro-Wilk test, it was seen that the data showed a normal distribution. Pearson correlation analysis was used to investigate the relationship between numerical variables. Multiple linear regression analysis included scales with a significant Pearson correlation according to univariate analysis. In the study, the effect between the total score averages of the scale and its sub-dimensions was examined by linear regression analysis. Mean ± standard deviations (mean ± SD) were given as descriptive statistics. Statistical analysis was performed with SPSS for Windows version 25.0, and a p-value < 0.05 was accepted as statistically significant.

Ethical Considerations

The ethics committee of a university gave ethics approval for the study to be conducted on

11/11/2021 (2021/27). The necessary permissions were electronically obtained from the authors who conducted the scale's reliability and validity study. The parents signed an informed consent form before beginning the study.

Results

All of the parents who participated in the study were mothers. When the medical diagnoses of the medical technology-dependent children of these mothers were examined, it was found that 13.4% (n = 22) were diagnosed with Cerebral Palsy, 9.1% (n = 15) were not diagnosed, 8.4% (n = 14) were diagnosed with Pulmonary Failure and Spinal Muscular Atrophy (SMA), 6% (n = 10) were diagnosed with Tracheomalacia, 3.6% (n = 6) were diagnosed with muscular diseases, 3.1% (n = 5) (the same rate for each diagnosis) with Mitochondrial myopathy, Moebius Syndrome, Down Syndrome, Mucopolysaccharidosis (MPS), West Syndrome, Tay-Sachs Syndrome, and 2.4% (n = 4) (the same rate for each diagnosis) diagnosed with Nager Syndrome, Nemaline Myopathy 2, Trisomy 10q, 1.8% (n = 3) (the same rate for each diagnosis) diagnosed with Spina Bifida, Rett Syndrome, Prune 1 Syndrome, Myastenia Gravis, I-cell (Mucolipidosis Type 1), 1.2% (n = 2) (the same rate for each diagnosis) diagnosed with Walker Warburg Syndrome and Treacher Collins Syndrome, 0.6% (n = 1) (the same rate for each diagnosis) were diagnosed with Alexander Disease, Sandhoff Syndrome, MECP2 Syndrome, NCL Batten Disease, Canavan Syndrome, Ohtahara Syndrome, Lissencephaly, and Beare-Stevenson Cutis Gyrata Syndrome.

In the study, it was found that the mean age of technology-dependent children and their parents was 35.03 ± 35.43 months, the mean age of the

Table 1. Socio-demographic Characteristics of the Parents and Their Children (n = 164).

Characteristics	Mean+SD	Min–Max
Mother's age	32.82+6.11	22–58
Father's age	36.65+6.84	25–63
Child's age (month)	35.03+35.43	2–216
Number of Siblings	4.07+1.05	2–8
Child's Weight (kg)	17.76+11.57	4–65
Child's Height (cm)	94.67+23.36	47–150
Duration of diagnosis (months)	22.88+22.87	1–136
Mother's Education Level	n	%
– Literate	2	1.2
– Primary School	27	16.5
– Secondary School	80	48.8
– University	55	33.5
Father's Education Level		
– Literate	2	1.2
– Primary School	32	19.5
– Secondary School	69	42.1
– University	61	37.2
Income Status of the Family		
– Income less than their expenditures	91	55.5
– Income equal to their expenditures	58	35.4
– Income more than their expenditures	15	9.1
Child's Gender		
– Female	78	47.6
– Male	86	52.4
Medical device used by the child		
– Household ventilator	131	79.9
– Oxygen Condenser	125	76.2
– Aspirator	157	95.7
– Saturation Device	150	91.5
– Feeding Pump	120	73.2

mothers was 32.82 ± 6.11 years, the mean age of the fathers was 36.65 ± 6.84 years, and the mean number of siblings was 4.07 ± 1.05, respectively. 48.8% of the mothers and 42.1% of the fathers were secondary school graduates; 55.5% of the families had incomes less than their expenditures; 52.4% were male; 95.1% used aspirators. The mean weight of the children was 17.76 ± 11.57 kg; their mean height was 94.67 ± 23.36 cm; the duration of the diagnosis was 22.88 ± 22.87 months; and the duration of dependence on the device was 20.30 ± 21.63 months (**Table 1**).

A negative significant moderate correlation was found between the total mean score of GSE, the total mean score of BHS, and the mean score of the perception of inadequacy subscale of BSFC. A negative, weak, significant correlation was found between the total mean score of GSE, the total mean score of BSFC, and the mean scores of the economic, social, physical, emotional, and time requirement subscales (**Table 3**).

It was determined that the total score of BHS accounted for 20% of the variation in the total score of GSE, and the total score of BSFC and its subscales accounted for 9% of the variation in the total score of GSE (**Table 4**).

A one-point increase in BHS reduced GSE by -1.047 points, whereas a one-point rise in BSFC increased GSE by 0.131. One point increase in the economic burden subscale of BSFC reduced GSE by -0.117 points, one point increase in the perception of inadequacy subscale reduced GSE by -0.662 points, one point increase in the social burden subscale reduced GSE by -0.132 points, one point increase in the physical burden sub-

Table 2. Total Mean Scores of the Scales and Its Subscales.

Scales	Mean+ SD	Min–Max
TotalBHS	7.750+4.297	0.00–19.00
TotalGSE	61.609+10.055	40.00–85.00
TotalBSFC	135.829+27.028	52.00–208.
BSFC Economic burden	20.128+4.723	6.00–30.00
BSFC Perception of inadequacy	22.823+5.867	10.00–39.00
BSFC Social burden	21.737+4.116	8.00–30.00
BSFC Physical burden	13.646+4.740	7.00–25.00
BSFC Emotional burden	35.603+8.466	12.00–55.00
BSFC Time requirement	21.890+7.532	7.00–35.00

Table 3. Correlation between Total Scores of GSE-BHS-BSFC and BSFC Subscales.

	TOTAL GSE	
	r	p
Beck Hopelessness Scale (Total Score)	-.448**	.000
BSFC economic burden	-.179*	.022
BSFC perception of inadequacy	-.315**	.000
BSFC social burden	-.189*	.016
BSFC physical burden	-.227**	.004
BSFC emotional burden	-.108	.167
BSFC time requirement	-.187*	.017
BSFC Total	-.254**	.001

r – pearson correlation

Table 2 shows the mean scores on all the scales and their subscales. The total mean scores of the participants were 7.750 ± 4.297 for BHS, 61.609 ± 10.055 for GSE, and 135.829 ± 27.028 for BSFC. Their mean scores for the BSFC subscales were 20.128 ± 4.723 for economic burden, 22.823 ± 5.867 for the perception of inadequacy, 21.737 ± 4.116 for social burden, 13.646 ± 4.740 for physical burden, 35.603 ± 8.466 for emotional burden, and 21.890 ± 7.532 for time requirement, respectively (**Table 2**).

Table 4. Linear Regression.

	GSE MODEL	
	Adjusted R^2	
BHS	.195	
BSFC	.088	
	B	p
BHS	-1.047	.000
BSFC Total	0.131	.276
BSFC Economic burden	-0.117	.635
BSFC Perception of inadequacy	-0.662	.003
BSFC Social burden	-0.132	.685
BSFC Physical burden	-0.473	.047
BSFC Time requirement	-0.138	.492

scale reduced GSE by -0.473 points and one point increase in the time requirement subscale reduced GSE by -0.138 points.

Discussion

The study revealed that the duration of dependence on a medical technological device in children was 20.30+21.63 months (**Table 1**). While Düzkaya et al. reported in their research that this rate was 85.63 ± 58.4 months, the study by Berry et al. reported that 57% of the cases were younger than 12 months [23,24]. These differences are thought to be associated with the treatment and care durations of the varying diagnoses of diseases in children. However, Gökalp reported that the children were dependent on a device for an average of 25 months, similar to this study.

It was determined that the mothers with medical technology-dependent children exhibited self-efficacy above the mean (**Table 2**). Toly et al. qualitatively examined the dimension of support given to mothers with technology-dependent children. They found that mothers were supported by their spouses most beneficially, improving their self-efficacy [10]. Suzuki et al. reported in their study that both domestic support and the support of the nurse in home care brought self-confidence in mothers and child caregivers [16]. It is reported that providing economic and psychological support before the child and family shift from the hospital to home would foster caregivers [19]. When literature is reviewed, it is believed that meeting the social, economic, emotional and medical care needs of the caregivers of technology-dependent children would personally empower them and enhance the quality of care delivered to the child. This study suggests that the high self-efficacy of mothers is correlated with their attitudes towards their maternal roles and their attachment patterns to their children.

According to the literature [18,25,26], it was determined that the care burden for families with technology-dependent children was above the mean. Additionally, when the subscales of care burdens (economic burden, perception of inadequacy, social burden, physical burden, emotional burden, and time requirement) were examined, it was found that they got a score above average in all subscales (**Table 2**). In their study, Türe et al. reported that the care burden of caregivers for children with chronic diseases was mild at the rate of 38.1%, moderate at the rate of 22.9% and severe at the rate of 39% [18]. In the study conducted by Baddour et al. on the caregivers for children dependent on home ventilators due to tracheostomy, they found that many parents had to resign from their jobs or worked less to care for their children. It is known that this condition imposes an economic and psychological burden on the family [19]. Choi et al. found in their study that the caregiver cared for the child for 14 hours a day, slept for 5.6 hours, and could allocate 2.4 hours for personal care, and care burdens precluded them from meeting their individual needs [20]. In their study, Edwards et al., (found that a significant majority of families had one or more members who quit their jobs, cut down work, or took weeks of unpaid leave from their workplace to care for their children [15]. Toly et al. investigated the adaptation of families who cared for children dependent on technology at home. They found that although mothers who adapted in a short time suffered less stress, the level of their depression was high. Mothers with more extend-

ed adaptation periods suffered more stress, and the level of their depression was also high [2]. Hefner and Tsai reported that at least one of the parents was a college or a university graduate, less than half of the families had economic hardship and cared for the child for more than 16 hours, leading them to feel depressed [27]. Similar to the previous studies, this study suggests that mothers had many different care burden problems and technology-dependent children who received home care/care, and their parents could not use social support systems and health care services as desired.

It was determined that families with technology-dependent children had hopelessness below the mean (**Table 2**). Toly et al. (2019b) found that when conflicts, complications, or anything related to care developed, it was difficult for mothers to maintain a positive attitude, increasing their hopelessness [4]. Nishigaki et al. (2016) reported in their study that mothers with children dependent on medical technological devices suffered from several physiological, sociological and psychological disorders, which also caused them to feel hopeless and that they should receive professional support [13]. It is reported that mortality rates of children dependent on medical technological devices during their follow-up at home are higher than the average population, and mortality rates in the first year vary between 0–10% [9]. Gökalp (2019) reported that 16.7% of children died in four years of follow-up, Koçkar et al. (2012) reported that 12.4% of children died in the first two years of follow-up, and Hsia et al. reported that 26.6% of cases died in long-term follow-up [28–30]. Although this study did not analyse mortality rates, it can be estimated that having a child in need of permanent care may raise the fear of losing the child at any time. It is thought that these persons responsible for primary care may suffer from individual, familial, economic, social and psychological problems and require support. This can be interpreted that in case of failure to meet this support sufficiently, the feeling of hopelessness in the individual would increase, and the whole family, including the child, would be negatively affected by this.

It was also found that as the mothers' self-efficacy increased, their hopelessness and care burden decreased (**Table 3**). The regression results indicated that the self-efficacy, hopelessness and care burden of the families with children dependent on medical technological devices were significantly affected [Table 4]. Looman et al. reported a positive correlation between the quality of life of children dependent on technological devices and their parents' physical, social, and cognitive functions [31]. Hefner and Tsai reported a correlation between the financial status of the family, the depression of the caregiver, and the unmet care needs of their children [27]. It was found that as maternal self-efficacy increased, the economic burden, social burden, physical burden, emotional burden, and time requirement in the family reduced (**Table 3**). According to the regression results, it was determined that while economic burden, social burden, physical burden, and time requirement were predicted, emotional burden was not (**Table 4**). Likewise, Choi et al.. They found that more than 80% of caregivers had physical and less economic and financial burdens [20]. The study by Edwards et al. reported that the family paid 3899 US dollars (calculated as the median) for the expenditures of children dependent on a home ventilator in the last three months [15]. It was reported that the financial stress in families decreased as their income level rose, and some families suffering from financial stress reported this stress to be caused by the spending they made out of their own pockets. Mothers' self-efficacy contributes to resilience in care burden and psychosocial health. When mothers were self-efficient, they were more self-sufficient in sub-parameters related to care burden, but they were unaffected by the emotional burden. This is associated with mothers' awareness that their children depend entirely on them for their needs, and they assume a conscientious responsibility.

Limitations

The study is subjective to the mothers in the sample group and cannot be generalised to all mothers who have children dependent on medical technological devices. The limitation of the study is the exclusion of fathers from the sample group since Turkey presents a patriarchal society, and fathers tend to work. At the same time, mothers play social roles, such as being responsible for the child's care.

Conclusions

One of the most vulnerable children is technology-dependent children at home. When these children are discharged home from the hospital, the family needs to be educated about care. In the hospital setting, it is necessary to initiate training, counselling, and psychosocial support for the caregivers and the entire family. Pediatric nurses play an essential role in achieving this.

Suggestions

It is believed that mothers should be personally supported, and their self-efficacy should be further improved in their relationships/communication with their spouses and other healthy children as well as the sick child in the hospital and during home care. Finding solutions to the needs of the caregiver and the family can provide excellent and planned care so that recurrent hospitalisations of the child can be avoided.

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Conflict of interest statement
The authors declare no conflict of interest.

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