Araştırma makalesi

Research article

Caregiver Burden and Quality of Life of Patient and Caregiver in Burns

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ABSTRACT

Aim: This descriptive study aimed to determine the relationship between burn patients and their caregivers' quality of life and care burden.

Material and Methods: The study was conducted at two university hospitals. Thirty burn patients discharged from the hospitals between September 2015 and January 2016 and their 30 caregivers participated in the study. Data were collected face-to-face with the datasheet for patients, the Burn-Specific Health Scale, the datasheet for caregivers, the World Health Organization Quality of Life (QoL)-Brief, and the Zarit Caregiver Burden Interview Scale.

Results: The patients' mean QoL scores, and sub-scores were higher than 0.53. The highest caregivers' mean QoL score was for the physical health domain (74.62±16.87). There was a negative correlation between the physical health scores of caregivers and the general health and overall QoL scores of patients ($p<0.01$). The mean caregiving burden score was 26.63±12.78. There was a negative correlation between the caregiving burden score, social health, and overall QoL scores of patients ($p<0.05$).

Conclusion: The patients demonstrated a moderate level of QoL, while their caregivers demonstrated a high level of QoL. The caregiver burden of the caregivers was low. There was a correlation between patients' QoL and their caregivers' QoL and caregiver burden. It is crucial to prepare the patients and their caregivers to increase QoL and decrease the caregiving burden.

Keywords: Burns, caregiver, caregiver burden, quality of life

ÖZ

Yanıkta Bakım Veren Yükü ile Yanık Hastasının ve Bakım Verenin Yaşam Kalitesi

Amaç: Bu tanımlayıcı çalışma yanık hastalarının ve bakım vericilerinin yaşam kalitesi ile bakım verme yükü arasındaki ilişkiyi incelemiştir.

Gereç ve Yöntem: Çalışma, iki üniversite hastanesinde yapılmıştır. Tedavi sonrası taburcu olan 30 yanık hastası ve onların 30 bakım vereni ile Eylül 2015-Ocak 2016 tarihleri arasında yürütülmüştür. Veriler, hasta veri formu, Yanığa Özgü Yaşam Kalitesi Ölçeği, bakım verici veri formu, Dünya Sağlık Örgütü Yaşam Kalitesi Ölçeği kısa formu ve Zarit Bakım Verme Yükü Ölçeği ile yüz yüze toplanmıştır.

Bulgular: Hastaların ortalama yaşam kalitesi puanları ve alt alan puanları 0.53'ün üzerinde bulunmuştur. Bakım verenlerin en yüksek yaşam kalitesi puanı fiziksel sağlık alanında 74.62±16.87 olarak ölçülmüştür. Bakım verenlerin fiziksel sağlık puanları ile yanık hastalarının genel sağlık ve toplam yaşam kalitesi puanları arasında negatif korelasyon saptanmıştır ($p<0.01$). Bakım verenlerin bakım verme yükü puan ortalaması 26.63±12.78 bulunmuştur. Bakım vericilerin bakım verme yükü puanı ile hastaların sosyal sağlık ve toplam yaşam kalitesi puanları arasında negatif korelasyon saptanmıştır ($p<0.05$).

Sonuç: Hastaların yaşam kalitesi orta düzeyde bakım verenlerin ise yüksek düzeyde bulunmuştur. Bakım verenlerin bakım verme yükü düşük saptanmıştır. Yanık hastasının yaşam kalitesi ile bakım verenin yaşam kalitesi ve bakım yüküyle ilişkili bulunmuştur. Bu sonuçlar, yanık hastalarının ve bakım verenlerinin yaşam kalitelerini artırmak ve bakım verme yükünü azaltmak için hazırlanmasının gerekliliğini vurgulamaktadır.

Anahtar kelimeler: Bakım verici, bakım yükü, yanık, yaşam kalitesi

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INTRODUCTION

Burns, accounting for an estimated 180 000 deaths annually worldwide, is the fourth most common problem, following traffic accidents, falls, and interpersonal violence[1,2]. Burn injuries, frequently encountered worldwide, are an important health problem that adversely affects the lifestyle of the individual and family by bringing physical, psychological, social, and economic changes[3,4]. Burns often result in significant morbidity, physical limitation, pain, limitations in activities of daily living, self-esteem, depression, negative social interaction, change of body image, increased anxiety, and impairment of emotional well-being[4-7].

All these consequences of burn injury affect patients during their treatment and care, especially in the rehabilitative phases. In the rehabilitative phase, care priorities are focused on helping the patient return to pre-injury life. It is aimed to maximize the patient's functional status and abilities, to help the patient cope with major life changes and adjust to the changes the injury has imposed[8,9]. All these can result in prolonged healing and affect the long-term quality of life (QoL) of the patient[6].

One way to increase the QoL of the patient is family support. Family support helps patients' recovery; so that, which contributes to patients' survival[10]. Social support also decreases the risk of long-term psychosocial problems, such as anxiety, posttraumatic stress disorder, and depression in patients with burns[10-12]. Family members who care for the patient after discharge perform the majority of care activities by themselves. Caring involves organizing and performing household chores, helping with self-care, and providing financial, medical, and psychological support. Providing this care brings about changes in the caregiver's work and family life. Caregivers also help patients with burns to reintegrate into society and improve their social relationships[3,10,12]. All of these activities cause observable changes in the QoL of the caregiver[3,13,14]. Studies conducted with caregivers demonstrate that health related QoL among family members of patients with burns is affected by physical, psychological, environmental, and social QoL[13]. The health-related consequences of burns, which affect QoL, can place a significant physical, psychological, and socioeconomic burden on the caregiver[5,14,15]. The increased burden with reduced QoL of caregivers may lead to decreased functionality and delayed recovery of the patients[16].

Study results show that burn injury affects both patient's[4,6,7,17] and family members' QoL[3,13,15,18]. However, it is not clear how the QoL of the patient with burns affects the caregiver's QoL and care burden. Knowing the relationship between the patient's QoL and caregiver's QoL and care burden, and the needs of caregivers may help to provide early attempts to support caregivers, as well as the patients.

Aim

The aim of this study was to determine the relationships among caregiver burden, caregiver QoL, and patient QoL in burns.

Research Questions

The study it was aimed to find responses to the following questions:

1. What is the level of QoL of patients and their caregivers?
2. What is the level of care burden of the caregivers?
3. Is there a relationship between the QOL of the caregivers and the patients?
4. Is there a relationship between the care burden of the caregivers and the QoL of the patients?

MATERIAL and METHODS

Study Design

This descriptive design was conducted with burn patients admitted to two university hospitals' burn unit/center in Turkey between September 2015 and January 2016 and their caregivers.

Study Sample

A total of 30 patients with burns and their 30 caregivers were recruited from two university hospitals in Ankara, Turkey. Inclusion criteria for patients were: (1) aged 18 years or older, (2) able to communicate, (3) no previous diagnosis of psychological problems, and (4) discharged at least 15 days ago. Inclusion criteria for caregivers were: (1) aged 18 years or older, (2) able to communicate, (3) no previous diagnosis of psychological problems, and (5) care for the patient for at least 15 days.

The sample size was calculated as a minimum of 29 individuals with $\alpha = 0.05$ error rate and 0.80 power ($1-\beta$) based on the intermediate-level (0.50) relationship, using Power Analysis and Sample Size (PASS) 2006 software (NCSS, LLC, Kaysville, Utah, USA).

Data Collection Tools

Instruments for Patients

Datasheet for patients: Datasheet consisted of two parts. The first part included nine questions on sociodemographic characteristics such as gender, age, marital status, occupation, number of children, educational level, co-existing health problems, and tobacco and alcohol consumption. The second part included seven questions on burn injury-related characteristics such as etiology, burn depth, burned total body surface area (TBSA), burned body part, the time elapsed after the burn, organ loss due to burning, and experienced burn trauma previously.

Burn-Specific Health Scale (BSHS): The scale was developed in the 1980s by Munster and colleagues as a self-reporting questionnaire to measure the QoL of adult patients with burns. The scale consists of 80 questions and includes four main domains: physical, social, mental, and general. The physical health domain has mobility and self-care, role activities, and hand-function sub-domains; the social health domain has sexual activity and family and friends sub-domains; the mental health domain has affective and body image sub-domains. The general health domain, which evaluates patients' general health concerns, includes no sub-domain. Responses to the items are pointed out on a five-point scale (0 = "extreme(ly)" to 4 = "no/none at all"). A score is calculated by dividing the total score for a domain or subdomain by the total possible score. The scale's scores range from 0.00 to 1.00. Higher scores indicate better quality of life. The alpha values, which show the reliability of the scale, were 0.83-0.92 for sub-domains[19]. The Turkish validity and reliability study was performed by Tuna and Cetin[17]. The alpha values of the reliability analysis of the scale were 0.95, 0.95, 0.87, 0.89, and 0.97 for the physical, emotional, social, and general health domains and overall QoL, respectively[17].

Instruments for Caregivers

Datasheet for caregivers: Datasheet consisted of two parts, each with seven questions. The first part included sociodemographic characteristics such as gender, age, marital status, educational level, income status, number of children, and employment status. The second part included caregiving characteristics such as relationship with the patient, duration of the care, living situation, resources to help for care, type of resources, the sufficiency of the resources, and difficulties experienced during the care.

World Health Organization Quality of Life-Brief (WHOQOL-Bref): The scale is a shortened version of the World Health Organization Quality of Life (WHOQOL) assessment form. The WHOQOL-Bref consists of 26 questions and has four QoL domains: physical health, social, psychological relationships, and environment. Responses to the items are pointed out on a five-point scale (1 to 5). The higher scores indicate a greater quality of life. Cronbach alpha values for each domain ranged from 0.66 to 0.84[20]. The Turkish validity and reliability study of the scale was conducted by Eser et al.[21]. In that study, the Cronbach alpha values were between 0.53-0.83[21].

Zarit Caregiver Burden Interview (ZCBI): The scale measures the difficulties experienced by caregivers. The scale was developed by Zarit, Reever, and Bach-Peterson in 1980 and consists of 22 items with responses based on a Likert-type scale, ranging from 0 (“never”) to 4 (“almost always”). The lowest score on the scale is 0, and the highest is 88. The items on the scale are primarily oriented toward the emotional and social aspects affected by caregiving, and higher scores indicate greater severity of problems. Cronbach's alpha coefficient of the ZCBI was 0.91[22,23]. The adaptation of the ZCBI to Turkish and its validity and reliability were conducted by İnci and Erdem. The alpha value indicating the internal consistency coefficient was set at 0.95[23].

Data Collection

The data were collected after obtaining IRB approvals and permissions from the study hospitals. Data collection tools were administered by the researcher (SK) through face-to-face interviews between September 2015 and January 2016. The details of the data collection process were as follows:

1. Address and telephone numbers of the patients meeting inclusion criteria were obtained from the units' discharge lists or patients’ files in the archive. Patients were called via phone and invited to the study. Patients who accepted were asked for their caregivers, meeting inclusion criteria, to participate in the study. After confirmation of the participants in the study through phone, appointment times and places were arranged. Those eight patients and their caregivers were visited at their homes. Twenty-two patients and their caregivers preferred to have met the researcher at the outpatient clinic during their follow-up appointment. Patients and their caregivers were met in a private room arranged for the study in both hospitals.
2. Before starting the meeting, written informed consent was obtained from each participant.
3. During the meeting, the first patients were interviewed alone. Because of privacy, the patients filled out the first part of the datasheet for the patient and the BSHS. If there were any confusing items of the BSHS, the researcher explained them. The second part of the datasheet for the patient was filled out from the patient's file in the hospital by the researcher. Filling the sheets took an average of 30 minutes.
4. During the meeting, secondly, the caregiver filled out a data sheet for caregiver, ZCBI, and WHOQOL-Bref, due to privacy. If there were any confusing items on the scales, the researcher explained them. Filling the sheets took an average of 25 minutes.

Data Analysis

Data were analyzed using IBM Statistical Package for the Social Sciences (SPSS) v.23 (IBM Corporation, Armonk, NY, USA). Descriptive statistics such as means, standard deviations, median, minimum and maximum values, percentages, and frequencies were used to describe the sample's demographic characteristics. The Shapiro-Wilks test was used to test normality. As the data were not normally distributed, the Spearman test was used to examine the relationships of QOLs of patients with burns and their caregivers and caregiver burden among the study participants, and this addressed questions 3 and 4. A p-value <0.05 was considered statistically significant.

Ethical Consideration

The study was conducted according to the Declaration of Helsinki. Ethical approval was obtained from Non-interventional Clinical Research Ethics Committee of Hacettepe University (Decision number: GO 15/429-13, Date: 16.09.2015). Before starting the study, all participants were informed about the study and gave written informed consent.

Limitations

The measurement was performed once in the rehabilitation phase. So, the results show the current QoL and caregiving burden.

RESULTS

The mean age of the patients was 32.53±11.59 years, and 80% were male. The majority had third-degree burns with greater than 20% of TBSA. Burns were caused mainly by flame while the upper body parts such as hands, arms, and face were affected. The mean age of the caregivers was 39.86±11.30 years, and 66.7% were female. Most of them were spouses or parents of the patients (Table 1).

The patients’ mean BSHS score was 0.66±0.15. The mean physical, mental, social, and general health domain scores were greater than 0.50 (Table 2). The highest caregivers’ mean WHOQOL-Bref score was in the physical health domain (74.62±16.87).

Table 1. Descriptive Variables of Patients with Burns and Their Caregivers (n=30)

Patients with Burns			**Caregivers**		
Age (years)	**n**	**%**	**Age (years)**	**n**	**%**
19-28	13	43.3	18-29	5	16.7
29-38	11	36.7	30-39	9	30.0
39-48	4	13.3	40-49	10	33.3
49-58	2	6.7	50-70	6	20.0
Gender			**Gender**		
Male	24	80.0	Male	10	33.3
Female	6	20.0	Female	20	66.7
Educational level			**Educational level**		
Illiterate	1	3.3	Illiterate/Literate	2	6.7
Elementary School	2	6.7	Elementary School	10	33.3
Secondary School	4	13.3	Secondary School	5	16.7
High School	11	36.7	High School	4	13.3
College/University	12	40.0	College/University	9	30.0
Employment			**Employment**		
Worker	11	36.7	Unemployed	18	60.0
Officer	7	23.3	Employee	8	26.6
Student	5	16.7	Unpaid leave due to care for	2	6.7
Soldier	5	16.7	Quit job due to care for	2	6.7
Retired	2	6.7			
Depth of burn			**Living situation**		
Second degree	5	16.7	Together	28	93.3
Third degree	21	70.0	Spare	2	6.7
Second and third degree	4	13.3			
Cause of burn			**Relationship with patient**		
Fire-Flame	17	56.7	Spouse/Partner	13	43.3
Electricity	7	23.3	Parent	12	40.0
Chemical	3	10.0	Relative	3	10.0
Boiled water	2	6.7	Daughter/Son	2	6.7
Hot oil	1	3.3			
Burned area*			**Difficulty in giving care***		
Hand/s	20	66.7	Bathing	20	66.7
Face	16	53.3	Dressing	18	60.0
Arm/s	15	50.0	Mobilizing	14	46.7
Leg/s	13	43.3	Feeding	12	40.0
Neck	8	26.7	Changing position	2	6.7
Foot/feet	5	16.7	Maintaining communication	2	6.7
Time after injury (days)			**Caregiving duration (days)**		
Median: 76 days (min: 25-max: 600)			Median: 40 days (min: 15-max: 400)		

*"n" is folded because participants responded more than once.

The mean ZCBI score of caregivers was 26.63±12.78 (Table 2).

Table 2. BSHS Scores of Patients with Burns, WHOQL-Bref and Zarit Caregiver Burden Interview Scores of Caregivers (n=30)

BSHS scores of patients with burns			
Main domains	**X±SD**	**Min**	**Max**
Physical health	0.53±0.28	0.01	0.98
Mental health	0.71±0.18	0.15	1.00
Social health	0.77±0.13	0.42	0.96
General health	0.62±0.17	0.16	0.93
Total score	0.66±0.15	0.23	0.89
WHOQOL-Bref scores of caregiving individuals			
Sub-domains	**X±SD**	**Min**	**Max**
Physical health	74.62±16.87	28.57	100
Psychological	68.22±14.76	29.16	100
Social relationships	63.75±21.88	25.0	100
Environment	56.34±17.56	27.77	91.66
Zarit Caregiver Burden Interview scores of caregiving individuals			
Total Score	X±SD	Min	Max
	26.63±12.78	10.0	65.0

BSHS: Burn Specific Health Scale, SD: Standart Deviation, WHOQOL-Bref: World Health Organization Quality of Life-Brief

The caregivers' physical health scores were negatively correlated with the patient's general health scores (r=-0.508, p<0.01) and total BSHS scores (r=-0.463, p<0.01). Caregivers' ZCBI scores were negatively correlated with the patient's social health scores (r=-0.426, p<0.05) and total BSHS scores (r=-0.396, p <0.05) (Table 3).

Table 3. Correlation Between Quality of Life of Patients with Burns and Quality of Life of Caregivers and Caregiving Burden (n=30)

		Domains of Quality of Life (WHOQL-Brief) of Caregivers						
Quality of Life of Patients with Burns		Physical health	Psychological	Social relationships	Environment	Zarit Caregiver Burden Interview Score	Days of care	Time after burn (day)
Burn Specific Health Scale (BSHS)	r	**-.463****	-.115	-.037	-.212	**-.396***	.127	.050
	p	**0.01**	0.546	0.845	0.261	**0.030**	0.505	0.790
Physical health	r	-.244	-.022	-.037	-.048	-.137	.031	-.006
	p	0.193	0.906	0.845	0.801	0.469	0.870	0.972
Mental health	r	-.212	.103	-.231	-.089	-.341	-.104	-.193
	p	0.260	0.589	0.220	0.640	0.065	0.583	0.306
Social health	r	-.165	-.061	-.051	-.078	**-.426***	.277	.169
	p	0.383	0.750	0.790	0.682	**0.019**	0.138	0.371
General health	r	**-.508****	-.109	-.129	-.150	-.303	.206	.114
	p	**0.005**	0.573	0.504	0.439	0.111	0.285	0.554
Zarit Caregiver Burden Interview Score	r	.274	-.195	-.285	-.348	1.00***	**-.468****	**-.507****
	p	0.143	0.301	0.127	0.060	-***	**0.009**	**0.004**
Days of care	r	-.285	.067	.096	.145	**-.468****	1.00***	-***
	p	0.126	0.725	0.614	0.444	**0.009**	-***	-***
Time after burn (day)	r	-.320	.235	.190	.320	**-.507****	-***	1.00***
	p	0.085	0.210	0.313	0.085	**0.004**	-***	-***

*Relationship is important at the level of 0.05. **Relationship is important at the level of 0.01. ***Same variable or no correlation.
WHOQOL-Bref: World Health Organization Quality of Life-Brief

DISCUSSION

The patients in the present study demonstrated a moderate level of QoL. They had the lowest QoL in physical health, similar to literature[4,17]. The physical domain is concerned with movement, self-care, hand function, and maintenance of activities of daily living[19]. Permanent damage due to burning injuries results in changes in daily functions and restricted mobility, preventing patients from performing activities of daily living independently and resulting in the reduced physical domain of QoL. On the contrary, they had the highest QoL in social health. The BSHS social health domain concerns family, friend relationships, and sexual intercourse[19]. Even though Turkey does not have a home care service for the follow-up of patients with burns after discharge, patients receive a great amount of social support from their family members. Family members who take on this role reintegrate patients into social life, making the patient's life much easier and happier.

This supportive environment and acceptance account for why patients with burns have better social health. Caregivers of patients with burns had low QoL in the environment domain (involving activities of daily living, leisure time, and access to information) and high QoL in physical health. Özdemir and Sarıtaş[13] reported that both female and male caregivers of patients with burns had a low score in the social domain and a high score in the physical health domain of QoL.

Because caregivers' daily life, working hours, and social activities may be restricted, and their routines may change[3,18], their QoL may be affected in the environmental domain. Caring for and supporting family members, spouses, children, or parents is normatively accepted as a duty in Turkish culture. And most of the caregivers were females, either the wife or mother of the patient, who were assigned caring roles. This degree of affinity and the duty of care assigned to females as part of a gender role may account for why caregivers report high self-efficacy and why they think the duty of care does not interfere with their physical lives.

The results showed that the patient’s general health, including well-being and pain, and global QoL were correlated with the caregiver’s physical QoL. It should be noted that caregivers of patients with burns are responsible for performing several complex tasks that significantly affect their lives. Some of those tasks include dressing wounds, feeding, bathing, providing a comfortable sleeping environment, and getting the patient to perform exercises. Caregivers assist patients with burns in their daily living and increase their well-being in the long term; however, their own lives and health are affected throughout the caregiving process. Therefore, although family support improves the QoL of the patient, the process poses challenges to the caregiver, and poor caregiver QoL can negatively affect the patient in turn.

The results showed that the caregivers had a low burden of care. Caregivers also reported that they had difficulty in bathing, dressing, mobilization, and feeding the patients. Burns are acute trauma; however, healing takes a long time. Prolonged wound healing causes physical problems such as deformities, contractures, scars, and itching, and psychological problems such as depression, body image disturbance, low self-confidence, and increased anxiety[4-7,24,25]. All these problems interfere with the patient's daily life. Therefore, caregivers have to manage many responsibilities (supporting the patients' daily activities, changing wound dressings, performing exercises, integrating into social life, doing her/his work, etc.) along with long-term burn rehabilitation. A large family structure and neighborhood relations provide support to caregivers in Turkey, allowing them to manage the care process without feeling overburdened. This study also revealed that the better the patient’s social and overall QoL, the less the caregiver’s care burden. Caregivers who witness patients recover with high QoL are more satisfied with the care that they provide, are less affected by the treatment process, and can cope with it more effectively.

CONCLUSION

It’s concluded that the QoL of patients with burns is affected at a moderate level. Their caregiver’s QoL is demonstrated at a high level, and the caregiver's physical health is negatively correlated with the patient’s general health and overall QoL. Also, caring for a patient with burns gives a burden at a low level, and the burden of the caregiver is negatively correlated with the patient’s social health and overall QoL.

The results of our study show that it is necessary to search for the determinants (subjective and objective factors) which influence the caregiver's QoL and caregiving burden. Nurses should prepare patients and their caregivers according to influencing factors for the difficulties and challenges they may encounter upon discharge from the hospital.

Ethics Committee Approval: Approval was obtained from the Non-interventional Clinical Research Ethics Committee of Hacettepe University (Decision number: GO 15/429-13, Date: 16.09.2015).

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Author contributions

Study design: SK, ZT
Data collection: SK
Interpretation of data: SK, ZT
Drafting manuscript: SK
Revising manuscript: ZT

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