Evaluation of the Quality of Life of Patients Who Use Intermittant Self-Catheterization by Themselves and by Their Caregivers

Temiz Aralıklı Kateterizasyon Uygulanan Hastaların Yaşam Kalitelerinin Kendileri Ve Bakım Verenleri Tarafından Değerlendirilmesi

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Özet

Amaç: Temiz aralıklı kateterizasyon (TAK) nörojenik mesanesi olan bireyler tarafından kullanılan bir cihazdır. TAK hasta veya bakıcı tarafından kullanılabilir. Bu çalışmanın amacı, TAK kullanan bireylerin TAK uygulama becerileri ile yaşam kaliteleri arasındaki ilişkiyi incelemektir.

Gereç ve Yöntemler: Haziran 2018 ve Mayıs 2019 tarihleri arasında, bir şehir hastanesi üroloji kliniğinde Temiz Aralıklı Kendi Kendine Kateterizasyon (TAK) kullanan 126 hasta çalışmaya dahil edildi. Tüm hastalar ISC-Q(T-ISC-Q) ve Qualiveen anketlerinin Türkçe versiyonunu doldurdu. TAK kullanıcıları iki gruba ayrıldı: Kendi kendine uygulayanlar ve bakım vericilerin ISC-Q ve Qualiveen arasındaki Spearman korelasyon katsayısı belirlendi.

Bulgular: Hastaların ortalama yaşı 51,53±16,47 yıl ve TAK kullanım süresi 42,15 ± 12,56 aydı. Toplam 72 hasta TAK uyguladığını bildirirken, bakıcı tarafından TAK uygulanan hasta sayısı 54 idi. ISC-Q puanları kullanım kolaylığı için 70,98±15,41, kolaylık için 42,85±18,40, mahremiyet için 75,71±14,97 ve psikolojik iyi oluş için 56,34±14,57 idi. Cronbach α sonuçları 0,782 idi. ISC-Q toplam puanı, Qualiveen toplam puanı ile pozitif korelasyon gösterdi (r=0,567, p=0,04). Kendi TAK kullanan hastalar, bakıcı tarafından TAK uygulanan hastalardan daha yüksek ISC-Q puanlarına sahipti.

Sonuç: Sonuç olarak, TAK kullanım

Abstract

Objective: The clean intermittent catheterization is a device used by individuals with neurogenic bladder. The ISC can be used by the patient or by a caregiver. The aim of this study is to examine the relationship between ISC practice skills and quality of life of individuals using ISC.

Material and Methods: Between June 2018 and May 2019,126 patients using Clean Intermittent Self Catheterization (ISC) in a city hospital urology clinic was included in the study. All patients completed the Turkish version of the ISC-Q(T-ISC-Q) and Qualiveen questionnaires. ISC users were divided into two groups: Self-administered and caregiver practitioners. Spearman's correlation coefficients between ISC-Q and Qualiveen were used.

Results: The mean age of the patients was 51.53±16.47 years, and the duration of ISC was 42.15 ± 12.56 months. A total of 72 patients reported that they performed the ISC, while the number of patients who underwent ISC by the caregiver was 54. ISC-Q scores were 70.98±15.41 for ease of use, 42.85±18.40 for convenience, 75.71±14.97 for privacy, and 56.34±14.57 for psychological well-being, respectively. The results of the Cronbach α was 0.782. ISC-Q total score was positively correlated with Qualiveen total score (r=0.567, p=0.04). Patients who used their own ISC had higher ISC-Q scores than patients who had ISC administered by the caregiver.

kolaylığı yüksek olmakla birlikte, TAK kullanan hastaların rahatlık ve psikolojik iyi oluşlarında azalma görülmektedir. Bu, bakıcı tarafından TAK uygulanan hastalarda daha düşüktü.

Anahtar Kelimeler: Aralıklı kendi kendine kateterizasyon, yaşam kalitesi, sonuç ölçüsü, bakım verici

Conclusion: As a result, while the ease of use of ISC is high, there is a decrease in the convenience and psychological well-being of the patients using ISC. This was lower in patients who had ISC administered by the caregiver.

Keywords: Intermittent self-catheterization, quality of life, outcome measure, caregiver

INTRODUCTION

A variety of diseases and events affecting the nervous system controlling the lower urinary tract (LUT) may cause neuro-urological symptoms (1). The resulting of these symptoms depends on mainly the location of the neurological lesion. For instance, the lesions, which locate above the pons or between the pons and the sacral cord, cause detrusor overactivity, resulting in urgency to void and urinary incontinence. Furthermore, lesions, which locate in the infra-sacral region cause noncontractile detrusor, resulting in increased residual urine. This increased residual urine may affect the upper urinary tract and cause to develop urinary tract infections (2). Therefore, it is crucial to empty the bladder in an effective way to prevent complications like infections. clean intermittent self-catheterization (ISC) is the most common minimally invasive procedure for the management of noncontractile bladder due to neuro-urological dysfunctions (3).

Although CISC provides great comfort to the patients to allow them to control when and where to empty their bladder without urinary leakage, it may impair the patients' quality of life (QoL) nonetheless (4). Bolinger et al. (5) suggested that the "out of home" situations may become stressful scenarios for some patients. The authors also reported that the steps of the ISC, which are hand sanitizing, cleaning the meatus, and lubricate the catheter, need some adequate countertops or shelves. However, the inadequately designed public bathrooms, make these steps difficult to do (6).

In 2012 Pinder et al. developed The Intermittent Self-Catheterization Questionnaire (ISC-Q) to evaluate these patients' QoL. Although ISC-Q is a reliable and well-validated questionnaire, its feasibility for evaluating patients with reusable catheters is not clear so far (7). Nevertheless, since it is a very valuable questionnaire, it was validated in many languages (8, 9).

The aim of this study is to examine the relationship between ISC practice skills and quality of life of individuals using ISC.

MATERIALS AND METHODS
The Study Protocol

We designed a cross-sectional study. Between June 2018 and May 2019, 126 patients; who performed ISC at least three times a day, were enrolled in the study. The present study protocol was reviewed and approved by the Ethics Committee of Okmeydanı Training and Research Hospital (approval No. 2018/930). Informed consent was obtained by all subjects when they were enrolled.

The patients, who were under 18 years of age, unable to read or to have a psycho-neurological illness, were excluded from the study.

In the demographic characteristics form, the patient's age, gender, education status, smoking-alcohol use status, reason for using ISC, frequency of using ISC, and whether he/she drives to walk or not were questioned. All patients fulfilled the Turkish version of the ISC-Q (T-ISC-Q) and Qualiveen questionnaires at the beginning of the study and four weeks later. Demographic data, the experience of ISC usage, and the daily frequency were recorded.

Intermittent Self-Catheterization Questionnaire

The ISC-Q contains four domains (ease of use, convenience, discreetness, and psychological well-being) with 24 entries. It allows the clinician to evaluate both the physical and psychological problems of the patient. A 5-point scale system is used for each entry from 0 to 4, which means strongly disagree and strongly agree, respectively. The scores are calculated for each domain separately by multiplying the mean value of the entries by 25. This calculation gives a value from 0 to 100. The total score is the simple average of all four domains' values. High values mean high QoL. Turkish validation of this questionnaire made by Yesil et al. (10).

Statistical Analysis

SPSS 23.0 software was used for data analyses (SPSS, Version 23.0; IBM Corp, Armonk, NY). To determine the distribution, the Kolmogorov-Smirnov normality test was performed.

Intraclass correlations coefficient (ICC) and Bland-Altman method were performed to assess the test-retest reliability (11, 12). Furthermore, Cronbach's α was used to evaluate the internal consistency of the T-ISC-Q domains and the total scale. Spearman's correlation analysis was performed to evaluate coefficients between ISC-Q and Qualiveen for the distinctive and convergent validity of the translated scale. Independent sample t test was used for comparisons.

RESULTS

The mean age of the patients was 51.53 ± 16.47 years, the duration of ISC was 42.15 ± 12.56 months, and the frequency was 5.14 ± 0.94 times/day. Most of the patients were male (66.7%, 84/126). The percentage of people using devices for walking was 33.3%. The demographic data of the patients were demonstrated in Table-1.

A total of 72 patients reported that they performed the ISC, while the number of patients who underwent ISC by the caregiver was 54. T-ISC-Q scores were 70.98 ± 15.41 for ease of use, 42.85 ± 18.40 for

convenience, 75.71 ± 14.97 for privacy, and 56.34 ± 14.57 for psychological well-being, respectively (Table-2). Cronbach α was 0.782. ICC was found as 0.713. T-ISC-Q total score was positively correlated with Qualiveen total score ($r = 0.567$, $p = 0.04$). Furthermore, convenience domain of the T-ISC-Q had a strong correlation with the Queliveen total scale ($p=0.001$) (Table-3).

Table 1. Demographic data of the patients (n=126)

	Mean±SD	Min-Max
Gender (male/female)	84/42	
Age (years)	51.53±16.47	21-86
Duration of ISC	42.15±12.56	2-84
Frequency of ISC times/day	5.14±0.94	3-7
Using the Walking Device (yes/no/%)	42/84 (33%)	
Smoking Status (yes/no)	40/86	
Alcohol Status (yes/no)	6/120	
Education Status (n-%)		
Primary	60	47.71%
High	36	28.57%
University	10	7.94%
Income Level (n-%)		
0-2000 TL	18	14.29%
2000-5000 TL	80	63.49%
>5000 TL	28	22.22%

Data are Mean ± SD or n (%).
ISC, clean intermittent self-catheterization.

Table 2. Intermittent Self-Catheterization Questionnaire scores

	Mean	SD	Min	Max
ISC(Easy To Use)	70.98	15.41	31.25	100.00
ISC(Convenience)	42.86	18.40	25.00	81.25
ISC(Discreetness)	75.71	14.97	50.00	100.00
ISC (Psychological Well-Being)	56.35	14.57	36.67	96.67
ISC(Total)	61.48	8.01	41.25	81.04

ISC, clean intermittent self-catheterization.

Table 3. Spearman correlations between Intermittent Self-Catheterization Questionnaire domains and total scores and Qualiveen® scores

		ISC (Easy to use)	ISC (Convenience)	ISC (Discreetness)	ISC (Psychological Well-Being)	ISC (Total)
Qualiveen Limitations	r	-0.101	**0.212***	-0.111	-0.138	-0.033
	p	0.286	**0.023**	0.241	0.143	0.729
Qualiveen Constraints	r	-0.118	0.018	0.012	-0.013	-0.046
	p	0.187	0.840	0.891	0.889	0.606
Qualiveen Fears	r	**-0.356****	**0.666****	**-0.496****	**-0.244***	-0.041
	p	**0.000**	**0.000**	**0.000**	**0.014**	0.684
Qualiveen Feelings	r	**0.286****	0.019	0.012	**0.274****	**0.302****
	p	**0.002**	0.838	0.897	**0.002**	**0.001**
Qualiveen Total	r	0.009	**0.306****	-0.091	-0.012	0.163
	p	0.922	**0.001**	0.322	0.895	0.074

*p<0.05

**p<0.01

ISC; clean intermittent self-catheterization,

Spearman correlation test

Table 4. Comparison between groups

ISC-Q Domains	Self-using	With caregiver	p
Ease of use	72.63 (18.01)	66.08 (17.44)	0.001
Discreetness	79.58 (20.07)	68.36 (24.50)	<0.001
Psychological well-being	59.76(18.88)	51.50 (25.31)	0.002
Convenience	44.55 (15.15)	39.03 (25.45)	0.001

Independent sample t test was used

ISC, clean intermittent self-catheterization

The ISC-Q all sub-dimension scores and the total score of the patients who used the ISC themselves were found to be higher than the patients who used the ISC with the help of their caregivers (Table-4).

DISCUSSION

According to our results, the quality of life was found to be higher in patients who used ISC themselves. In addition, the privacy of the patients is affected during ISC administered by the caregiver.

The use of ISC is a process that can be done in many steps and where effective hand hygiene plays a role. Although a lot of training is provided, its incorrect

application can lead to deterioration of the patient's quality of life and infections. Videos containing ISC training can be preferred by patients and caregivers in terms of ease of application(13).

Based on literature, the validity of a translated scale should be evaluated by using the gold standard tool (14); however, in the time being, there was no validated ISC related QoL questionnaire in Turkey. Nevertheless, according to our findings, the total T-SCI-Q correlated with Qualiveen. Furthermore, Pinder et al. proved the robust relationship between ISC-Q and Qualiveen in a previous study (7). Therefore, we assumed that our findings are consistent with the

literature. However, the discreetness domain of the T-ISC-Q did not correlate with the other domains but the fear domain of Qualiveen. In our opinion, this could indicate that the discreetness domain may reflect concerns about ISC in cultural background (10). As far as we know, the concept of discreetness can vary in different geographies (15). Therefore, it is reasonable to accept that the discreetness domain may be the most subjective in the scale. Furthermore, Yoshida et al. also reported similar results about the discreetness domain on Japanese users in a recent study (9). There was a negative correlation between Qualiveen -fear sub-dimension and all sub-dimensions of ISC-Q in patients. Patients' fears and concerns about the use of ISC reduce ease of use, reduce usefulness and psychological well-being. These results are similar to previous findings. In addition, it was observed that these scores were lower in patients who underwent ISC by their caregivers. This situation is thought to be related to the anxiety and fear that the patients experience because of the inability to hide their privacy.

However, we have some limitations that need to be addressed. First, the patients' data are from one hospital. Therefore, the generalizability of our findings is limited. Furthermore, all patients were disposable catheter users, and our validated scale was not tested on reusable catheter users. Therefore, it is not clear whether T-ISC-Q can be beneficial to assess the ISC-related QOL of different kind of catheter users.

CONCLUSION

To conclude, while the ease of use of ISC is high, there is a decrease in the convenience and psychological well-being of the patients using ISC. This was lower in patients who had ISC administered by the caregiver.

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