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AN INVESTIGATION OF QUALITY OF LIFE RELATED TO PROSTHESIS IN SYRIAN REFUGEE LOWER EXTREMITY AMPUTEES

ORIGINAL ARTICLE

ABSTRACT

Purpose: The use of prosthesis and an individual's perception of the prosthesis are associated with the quality of life. The study aimed to evaluate the quality of life related to prosthesis in Syrian refugees with lower extremity amputees.

Methods: The study was conducted at three different prosthetic-orthotic centers managed by the Alliance of International Doctors. Seventy-six male (age=37.76±12.83 years) and 12 females (age=37.16±16.07 years) Syrian refugees with unilateral lower extremity (transtibial and transfemoral/knee disarticulation) amputation were evaluated. Demographic and amputation and prostheses-related characteristics were recorded. Quality of life related to the prosthesis was evaluated using the Prosthetic Evaluation Questionnaire (PEQ).

Results: All PEQ scores of the transtibial and transfemoral/knee disarticulation amputees were similar (p>0.05). The PEQ-Appearance score of the single amputees was observed to be significantly lower than the married amputees (p=0.013). The PEQ-Ambulation score of participants using prosthesis over one year was significantly higher (p=0.038). The PEQ-Sound score of participants using prosthesis less than one year was found significantly higher (p=0.048). The PEQ-sound scores of chronic disease group were significantly higher than those of accident and war associated amputees (p=0.020).

Conclusion: Quality of life of the refugee amputees regarding prosthesis and living with a prosthesis were similar regardless of the level of amputation. Expectations change with the increase in the duration of prosthesis use, and in single amputees, the expectation of cosmetic appearance becomes a concern.

Key Words: Amputees; Prosthesis; Quality of Life.

SURİYELİ MÜLTECİ ALT EKSTREMİTE AMPUTELERİNDE PROTEZE BAĞLI YAŞAM KALİTESİNİN ARAŞTIRILMASI

ARAŞTIRMA MAKALESİ

ÖZ

Amaç: Protez kullanımı ve bireyin protez algısı yaşam kalitesi ile yakından ilişkilidir. Bu çalışmanın amacı, Suriyeli mülteci alt ekstremite amputelerinde proteze bağlı yaşam kalitesini araştırmaktı.

Yöntem: Çalışma, Uluslararası Doktorlar Derneği tarafından yönetilen üç farklı protez-ortez merkezinde yapıldı. Tek taraf alt ekstremite amputasyonu (transtibial ve transfemoral/diz dezartikülasyonu) geçirmiş 76 erkek (yaş=37,76±12,83 yıl) ve 12 kadın (yaş=37,16±16,07 yıl) Suriyeli mülteci ampute dahil edildi. Demografik veriler, amputasyon ve protez ile ilgili özellikler kaydedildi. Proteze bağlı yaşam kalitesini değerlendirmek için Protez Değerlendirme Anketi (PDA) kullanıldı.

Sonuçlar: Transtibial ve transfemoral/diz dezartikülasyonu olan amputelerin tüm PDA puanları benzer bulundu (p>0,05). Bekar olan bireylerin PDA-Görünüş puanının evlilere göre anlamlı derecede düşük olduğu gözlendi (p=0,013). Bir yıldan uzun süredir protez kullananlarda PDA-Ambulasyon puanının anlamlı derecede yüksek olduğu bulundu (p=0,038). Bir yıldan kısa süredir protez kullananların ise, PDA-Ses puanı anlamlı derecede yüksekti (p=0,048). PDA-Ses puanı kronik hastalık nedenli amputasyonlarda, kaza ve savaş nedenli amputasyonlara göre anlamlı olarak daha yüksekti (p=0,020).

Tartışma: Mülteci amputelerin, protezleri ve yaşam kalitesi ile ilgili algılarının, amputasyon seviyesinden bağımsız olarak, birbirine benzediği bulundu. Protez kullanım süresinin artışı ile beklentilerde değişim görülmekte ve bekar bireylerde görsellik beklentisi ön plana çıkmaktadır.

Anahtar Kelimeler: Ampute; Protez; Yaşam Kalitesi.

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INTRODUCTION

Quality of life is defined as a person's perceived position concerning his/her aims, expectations, conditions, and concerns within the scope of the values and culture of the person's habitat (1). Physical health is influenced by the level of independence, psychological condition, social relationships, individual beliefs, and the living environment. Amputation causes substantial changes in a person's daily life and function levels (2). The amputee faces many challenges to return the pre-operative functional levels, and the limitations in maintaining physical function affect the quality of life adversely (3). Therefore, one of the aims of the rehabilitation programs in lower limb amputees with prosthesis is to maintain the quality of life (4).

The use of prosthesis and the individual's perception of the prosthesis are associated with the quality of life (5). Prosthesis usage restores the body image, gives a cosmetically acceptable appearance, and improves function (6). In addition, the type and quality of prosthesis plays a vital role in the individual's perception of life and his/her quality of life (2,4)

In Arabic-speaking countries, the incidence of diabetes-related amputation is the highest (7,8). In addition to this, other causes such as terror incidents and wars have been steadily increasing (9,10). A substantial number of amputees reside in Arabic-speaking countries, and some of them were forced to leave their homes and live as refugees in other countries. It is crucial to investigate how the amputation level, cause, and other descriptive variables efect quality of life in the refugees with amputees. The present study aimed to investigate the quality of life as well as their perceptions related to prosthesis using the Prosthesis Evaluation Questionnaire (PEQ) in Syrian refugees with lower extremity amputees.

METHODS

The study was a cross-sectional multi-centered study. The study was conducted on three different prosthesis-orthosis centers (Istanbul, Sanliurfa, and Reyhanli) operating by the Alliance of International Doctors, an international non-governmental organization, between February 2, 2019, and December 7, 2019. The study included 88 Syrian refugees with unilateral lower extremity (transfemoral/knee disarticulation, TFA/KD, and transtibial, TTA) amputees in an age range of 18-74 years, wearing prostheses at least 8 hours/day, and with perception and mental competence to understand and answer Arabic questions. The sample size was calculated using Power and Sample Size Program (Version 3.1.2, Tennessee, USA) based on a previous study and determined as 24 amputees for each group (TTA-TFA/KD) (95% power and α=0.05 Type I error probability) (11). Upper extremity, Chopart, ankle/hip disarticulation, and bilateral/multiple lower extremity amputees were not included in the study. All amputees participated in a similar prosthetic rehabilitation program planned by the same physician and physiotherapist, on average, 6-8 sessions.

Marmara University Faculty of Medicine Ethics Committee of Non-Interventional Clinical Research approved the study (Approval Number: 09.2019.004 and Approval Date: 04.01.2019). After obtaining written consent from the amputees, data collection was started. During the evaluation, a native Arabic speaking interpreter and was familiar with prosthesis terminology provided communication with the participants.

Demographic and descriptive data, such as the cause/level of amputation, kind of prosthetic components, the duration of the prosthesis use, marital status, education status, and employment status of the subjects were collected.

The PEQ was used to assess the quality of life-related to the prosthesis. The PEQ, developed by the Prosthetics Research Study (PRS) group, is a comprehensive self-report measurement tool to assess the functional level and prosthesis-related quality of life in lower extremity amputees (4,12). Day and Buis conducted the validity study of the Arabic version of the scale (13). Permission was obtained from Day and Buis for the use of the scale in the present study. The PEQ is composed of 82 questions with nine subgroups, including Frustration, Perceived Response, Social Burden, Ambulation, Utility, Residual Limb Health (RLH),

Table 1: Socio-Demographic and Amputation-Related Characteristics of the Amputees.

Characteristics	Amputation Level		Marital Status		Duration of Prosthesis		Cause of Amputation			Gender		Employment Status	
	TTA (n=48)	TFA/KD (n=40)	Married (n=69)	Single (n=19)	<1 Year (n=32)	≥1 Year (n=56)	Accident (n=15)	War (n=61)	Chronic Disease (n=12)	Female (n=12)	Male (n=76)	Unemployed (n=68)	Employed (n=20)
Age (years), Mean±SD	40.23±14.45	34.63±10.98	41.01±12.49	25.57±7.60	38.62±14.88	37.14±12.27	36.46±10.23	33.96±10.82	58.08±8.79	37.16±16.07	37.63±12.83	38.54±14.36	34.75±7.82

Amputation level-mean age p=0.048*; Marital Status *p<0.001; Cause of Amputation *p<0.001, TTA: Transtibial Amputee, TFA/KD: Transfemoral Amputee/Knee Disarticulation.

Table 2: Prostheses-Related Characteristics of the Amputees.

Components	Suspension n (%)				Foot n (%)				Knee n (%)			
	Active Vacuum	Passive Vacuum	Pin Lock	Suction	Sach	Single Axis	Dynamic	Carbon	Monocentric Friction	Hydraulic	Pneumatic	Micro Processor
TTA	7 (14.6)	8 (16.7)	33 (68.8)	0	3 (6.3)	23 (47.9)	14 (29.2)	8 (16.7)	0	0	0	0
TFA/KD	0	0	24 (60)	16 (40)	4 (10)	16 (40)	16 (40)	4 (10)	15 (37.5)	4 (10)	20 (50)	1 (2.5)

TTA: Transtibial amputee, TFA/KD: Transfemoral/knee disarticulation amputee.

Table 3: Prosthesis Evaluation Questionnaire Scores by the Amputation Levels.

Prosthesis Evaluation Questionaire	TTA (n=48)	TFA/Knee Disarticulation (n=40)	p
Ambulation	6.12±2.55	5.94±2.52	0.741
Transfer	7.29±2.36	6.96±2.21	0.489
Utility	7.46±1.85	7.10±2.28	0.407
Satisfaction	7.50±2.20	7.33±2.46	0.738
Prosthetic Care	8.15±2.04	8.20±1.70	0.918
Appearance	7.59±2.09	7.50±2.14	0.846
Sounds	7.16±2.80	7.36±2.44	0.726
Residual Limb Health	6.95±2.02	6.56±1.96	0.365
PEQ-PF	7.29±1.79	7.13±1.87	0.681
PEQ-MS	6.71±2.21	6.45±2.14	0.577

Student t Test. TTA: Transtibial Amputee, TFA: Transfemoral Amputee, PEQ-PF: Prosthesis Evaluation Questionnaire- Prosthetics Function, PEQ-MS: Prosthesis Evaluation Questionnaire-Mobility Scores.

Appearance, Sounds, and Well-being. There are also specific questions in the PEQ related to satisfaction, pain, transfer, prosthetic care, self-efficacy, and importance questions (14). In the present study, PEQ-Ambulation, PEQ-Appearance, PEQ-RLH, PEQ-Sounds, and PEQ-Utility and the questions related to transfer, prosthetic care, and satisfaction were evaluated. All questions use a Visual Analogue Scale (VAS, ranging from 0-the lowest score to 10-the highest score) and refer to four weeks preceding the administration of the instrument (12). The scores for each subgroup were generated by computing the arithmetic mean of all questions, and at least half of the questions of a single group should be answered with a number score (14). Furthermore, PEQ-Prosthetics Function Score (PEQ-PF) and PEQ-Mobility Score (PEQ-MS) were calculated. The PEQ-PF Score was calculated as the mean score of the values obtained in PEQ-Appearance, PEQ-RLH, PEQ-Sounds, and PEQ-Utility. The PEQ-MS combined the PEQ-Ambulation and Transfers subgroups (4).

Statistical Analysis

Statistical analyses were performed using IBM SPSS Statistics for Windows (Version 21.0. IBM Corp., Armonk, NY, USA). Descriptive statistics were used to categorize the amputees. Student t-test was used binary comparisons. Kruskal Wallis test was used for the multi-group comparisons, and Mann-Whitney-U test was used as post hoc. In this study, the significance level was determined as $p<0.05$ for all evaluations.

RESULTS

The mean age of the amputees (12 females, 76 males) was 37.68±13.22 years. Socio-demographic and amputation-related characteristics of the amputees are shown in Table 1. According to age outcomes, amputation level, marital status, cause of amputation showed difference between intra-classification of the related parameters ($p=0.048$, $p<0.001$, $p<0.001$ respectively). The gender, duration of prothesis and employment status were similar between the groups ($p=0.884$, $p=0.616$, $p=0.262$ respectively). The prostheses-related characteristics of the amputees are presented in

Table 4: Comparison of Prosthesis Evaluation Questionnaire Scores by Educational Status.

PEQ	Illiterate (n=11)	Elementary (n=19)	Secondary (n=29)	High School (n=22)	Undergraduate/ Graduate (n=7)	p$^{\phi}$
PEQ-PF	7.57±2.29	2.29±2.17	7.32±1.42	7.15±1.71	6.23±1.98	0.416
PEQ-MS	6.84±2.59	7.12±2.32	6.62±1.81	6.25±2.26	5.76±2.41	0.462

$^{\phi}$Kruskal Wallis Test. PEQ-PF: Prosthesis Evaluation Questionnaire-Prosthetics Function, PEQ-MS: Prosthesis Evaluation Questionnaire-Mobility Scores.

Table 5: Comparison of Prosthesis Evaluation Questionnaire Scores by Gender.

Prosthesis Evaluation Questionnaire	Total (n=88)	Female (n=12)	Male (n=76)	p
Ambulation	6.04±2.53	6.08±3.04	6.03±2.46	0.951
Transfer	7.14±2.29	6.25±2.95	7.28±2.16	0.146
Utility	7.30±2.05	7.58±1.62	7.25±2.12	0.606
Satisfaction	7.42±2.31	7.51±2.09	7.41±2.36	0.895
Prosthetic Care	8.17±1.88	7.75±1.90	8.24±1.88	0.403
Appearance	7.55±2.10	7.37±2.12	7.58±2.11	0.747
Sound	7.25±2.62	6.89±2.46	7.31±2.67	0.618
Residual Limb Health	6.77±1.99	6.33±2.62	6.85±1.88	0.402
PEQ-PF	7.22±1.82	7.04±1.94	7.24±1.81	0.721
PEQ-MS	6.59±2.17	6.17±2.87	6.66±2.06	0.467

Student t Test. PEQ-PF: Prosthesis Evaluation Questionnaire-Prosthetics Function. PEQ-MS: Prosthesis Evaluation Questionnaire-Mobility Scores.

Table 2.

The PEQ-PF and PEQ-MS scores were found to be similar in all subgroups in terms of TTA and TFA/KD. In the PEQ subgroups, even though statistically insignificant, scores of the TFA/KD group were trended to be lower (p>0.05) (Table 3). The PEQ-PF and PEQ-MS values of the amputees with various educational status were found to be similar (p>0.05) (Table 4). All PEQ scores of the male and female amputees were found to be similar (p>0.05) (Table 5).

In terms of all PEQ subgroup scores, except for PEQ-Appearance (p=0.013) and PEQ-PF (p=0.031), there was no difference between single and married amputees (p>0.05) (Table 6).

It was observed that the mean PEQ-Ambulation scores of amputees using prosthesis for more than one year were found to be significantly higher (p=0.038). On the other hand, the mean PEQ-Sounds scores of those with prosthesis for less than one year were significantly higher (p=0.048) (Table 6). Even though no difference was observed in multiple comparisons of the groups, the difference between an accident, war, and chronic disease groups was found to be significant in terms of the PEQ-Sounds scores (p=0.020). In terms of the employment status, all subgroups showed similar PEQ scores (p>0.05) (Table 6).

DISCUSSION

In the study, PEQ scores were found to be above average. The satisfaction level was excellent in terms of the characteristics evaluated. All PEQ subgroups, PEQ-PF, and PEQ-MS scores of the TTA and TFA/KD amputees were found to be similar. We found that the amputation level did not affect the quality of life. The quality of life was similar according to gender and education level. Expectations change with the increase in the duration of prosthesis use, and in single amputees, and the expectation of cosmetic appearance becomes a concern.

In previous studies, quality of life, prosthesis compatibility, and duration of daily prosthesis use the TFA have been reported to be lower (15,16). The PEQ scores of the amputees with different levels of amputations were similar. The scores of the TTA were tended to be higher than those of the TFA (3,17,18). The lower scores of the TFA/KD overlap with previous studies.

Despite difficulties associated with transfemoral prosthesis production and with meeting the prosthesis expectation of TFA/KD, the similarities of PEQ scores of TFA/KD and TTA showed that the prosthesis for TFA/KD reached a level similar to TTA in meeting the expectations of the amputees.

A meaningful relationship between prosthesis mobility and satisfaction with life has been shown (17). The PEQ-MS scores of the present study were found to be similar to the results reported by Franchignoni et al. (12) but lower than those reported by the other studies (4,5,16,19). The PEQ-

Table 6: Comparison of Prosthesis Evaluation Questionnaire Scores by the Descriptive Characteristics.

Prosthesis Evaluation Questionnaire	Marital Status			Duration of Prosthesis			Cause of Amputation				Employment Status		
	Married (n=69)	Single (n=19)	p$^{\delta}$	<1 year (n=32)	≥1 year (n=56)	p$^{\delta}$	Accident (n=15)	War(n=61)	Chronic Disease (n=12)	p$^{\phi}$	Unemployed (n=68)	Employed (n=20)	p$^{\delta}$
Ambulation	6.14±2.53	5.86±2.53	0.491	5.30±2.90	6.46±2.20	**0.038***	6.50±2.20	5.97±2.41	5.85±3.52	0.754	6.05±2.57	5.98±2.44	0.910
Transfer	7.27±2.34	6.67±2.48	0.313	6.91±2.40	7.27±2.32	0.479	6.33±2.36	7.36±2.21	7.04±2.59	0.242	6.99±2.33	7.66±2.13	0.253
Utility	7.50±2.05	6.57±1.97	0.083	7.07±2.09	7.42±2.03	0.449	6.80±2.34	7.39±1.82	7.44±2.83	0.468	7.37±2.04	7.04±2.13	0.533
Satisfaction	7.56±2.35	6.94±2.16	0.303	6.87±2.60	7.73±2.08	0.093	7.40±2.16	7.50±2.22	7.07±3.03	0.863	7.50±2.35	7.16±2.19	0.563
Prosthetic Care	8.18±2.00	8.14±1.37	0.929	7.94±2.00	8.30±1.80	0.387	7.31±2.66	8.38±1.56	8.21±2.08	0.167	8.30±1.72	7.55±2.34	0.255
Appearance	7.84±1.97	6.50±2.29	**0.013***	7.66±1.95	7.48±2.19	0.709	6.93±2.77	7.49±2.01	8.62±1.20	0.153	7.57±2.04	7.48±2.34	0.857
Sounds	7.50±2.55	6.33±7.77	0.086	7.89±1.78	6.88±2.95	**0.048***	6.50±3.13	7.16±2.55	8.62±1.94	**0.020***	7.37±2.55	6.83±2.90	0.425
Residual Limb Health	6.91±1.91	6.29±2.22	0231	6.94±2.07	6.67±1.95	0.547	6.43±2.77	6.65±1.97	7.86±1.89	0.131	6.80±2.10	6.69±1.61	0.830
PEQ-PF	7.44±1.74	6.42±1.89	**0.031***	7.39±1.63	7.12±1.92	0.499	6.67±2.35	7.17±1.64	8.13±1.75	0.104	7.28±1.78	7.01±1.97	0.565
PEQ-MS	6.71±2.11	6.18±2.40	0.351	6.10±2.50	6.86±1.93	0.115	6.41±2.15	6.66±2.04	6.45±2.94	0.908	6.52±2.21	6.82±2.08	0.593

*p<0.05. $^{\delta}$Student t Test. $^{\phi}$Kruskal Wallis Test. PEQ-PF: Prosthesis Evaluation Questionnaire- Prosthetics Function. PEQ-MS: Prosthesis Evaluation Questionnaire-Mobility Scores.

MS scores vary in relation to the amputation level, cause of amputation, mobility level, or mobility device use status (3,18,19). In the present study, amputation levels and causes did not significantly affect PEQ-MS scores.

Amputation limits opportunities in educational and vocational improvement (2). The majority of the amputees in the present study were found to be young. The cause of amputation was mainly the war (69%) for these amputees. In the present study, no difference was found between amputees with different education levels in terms of PEQ scores. Getting an education and qualified jobs would be one of the main issues in short. Being an amputee, in addition to being a refugee, would multiply the challenges they would need to face in the future.

In previous studies, the number of male participants has been reported to be in large quantities (71-94%) (4,5,19,20). The overwhelming majority of the male amputees in the present study were similar to the previous studies. The role of the males is vital in societies in which males have the primary responsibility for maintaining family standards. Amputation may prevent this responsibility. Therefore, functional aspects of the prosthesis are very crucial, especially for the males to maintain the financial sufficiency of the family and to overcome strenuous activities (21,22). On the other hand, aesthetic or cosmetic aspects of the prosthesis and its realistic appearance are crucial, especially for the females to be able to wear feminine outfits (6,21,23). In previous studies, only functionality and body image satisfaction are correlated in males. However, in females, along with functionality, aesthetics, and weight are correlated with body image (23). In another study, the success rate of prosthetic applications in females was reported to be lower. In the same study, although it was highlighted that females live alone more than males, it was argued that the gender is an independent and essential factor for the success of prosthesis (22). The females' PEQ-PF scores in general and the ambulation parameter score in the PEQ-MS were found to be significantly lower (4). In another study, no difference was found between genders in terms of prosthesis satisfaction, comfort, appearance, ease-of-use, or weight (24). The mean age of the participants was low and close to each other, and it could be a factor that would eliminate the gender difference in terms of mobility scores in the study.

The rate of married amputees in the present study (78.40%) was lower than those reported in studies by Legro et al. and Asano et al (4,5). Although mean PEQ-MS values in both single and married groups were similar, PEQ-PF mean values of the married group are significantly higher, which indicated that the expectations for the prosthesis were met in married participants.

Except for appearance, in all PEQ subgroups, single and married amputees showed similar results. In the present study, the mean age of the single amputees was lower. Their higher aesthetic expectation may have influenced the PEQ-Appearance score.

The mean PEQ scores were similar in terms of the duration of prosthesis use. However, mean PEQ-Ambulation scores were lower in those using the prosthesis for less than one year. In the first year of prosthesis use, habitual use of prosthesis is not established yet, problems such as volume changes of the stump are seen, and socket-stump compatibility is not established (25).

The PEQ-Sounds scores of those with prosthesis for more than one year were found to be lower. Prosthesis use focuses on ambulation and socket compatibility in early periods. With the experience in prosthesis use gained in time, expectations from prostheses increase, and mechanical sounds coming from the prosthesis may disturb the amputee. In the present study, similar models/types of products were selected for prosthetic feet and joints.

In the present study, we found that only the chronic disease group's satisfaction was higher in terms of the PEQ-Sounds parameter. The higher mean age in the chronic disease group may have resulted in higher prosthesis functionality satisfaction despite decreased mobility. The low number of amputees in the injury and chronic disease groups should also be considered when interpreting the results.

Amputation has a direct effect on employment status. In a previous study, 82% of the amputees became unemployed after amputation (2). Amputees have been reported to be generally unemployed (48-87.1%) (2,4,5,20). The unemployment rate

(68%) found in the present study was close to the those reported in the literature. The importance of social support after amputation in increasing the quality of life has been shown. Socialization is positively affected by social support and the increase in mobility (5). Those amputees receiving their prosthesis from a foundation were more satisfied with the look of their prosthesis (24). Our findings revealed that all subgroups had similar satisfaction levels, probably stating that providing the prosthesis free of charge increases the level of satisfaction (4,24). The selection of components was based on the mobility levels of amputees. However, novel products that provide high-level functionalities, such as carbon feet/microprocessor knees, have been used in few amputees. However, it was observed that the expectations of the unemployed/employed group were met at a similar level.

The limitation was that the present study was not able to form groups that were equal in terms of group size.

In conclusion, it was found that perceptions of refugee amputees, whose basic needs were fulfilled and who were living under similar conditions, regarding the prosthesis in general and living with prosthesis were generally similar to each other. Cause and level of amputation is not a factor, even though there were some differences in the subgroups. Despite the difficulties caused by being a refugee, providing functional prostheses free of charge might be a determining factor in this perception. With the increase in the duration of time in prosthesis use, expectations might change. Aesthetic expectations are of importance for single amputees. The increase in the number of refugee amputees in neighboring countries due to the civil war results in the necessity of taking new approaches and measures in the rehabilitation of these groups carrying cultural differences. It is essential to investigate how the cause/level of amputation and other descriptive variables affect prosthesis in these groups.

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Conflict of Interest: The authors report no conflicts of interest.

Ethical Approval: The Ethics Committee of Non-Interventional Clinical Research of Faculty of Medicine, Marmara University, approved the study (Approval Date: 04.01.2019 and Approval Number: 09.2019.004).

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