



## Original Article

# Quality of Life (QoL) Among Ostomized Patients – a cross-sectional study using Stoma-care QoL questionnaire about the influence of some clinical and demographic data on patients' QoL

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## ABSTRACT

**Introduction:** In Portugal around 20,000 individuals are ostomized, with all the associated changes in patients' everyday life that can compromise their Quality of Life (QoL).

**Objectives:** Assess and compare QoL of a group of ostomized patients according to sex, age group, type of surgery, primary disease, stoma duration and stoma type.

**Material and methods:** Ostomized patients observed in Stomatherapy department in between January 1st and May 30th 2017 was enrolled. QoL was assessed using the questionnaire Stoma Care QoL Questionnaire). Four domains were evaluated: Self-esteem and Self-image – SeSi Score; relation with Family and Friends – FF Score; relation with Sleep and Fatigue – SF score and ostomy Device Functioning insecurities – DeF score.

**Results:** Urostomy patients had significantly higher Total Scores, SeSi and FF scores than colostomy and ileostomy patients. Regarding SeSi Score, patients aged 70 years old or more and malignant diseases presented significantly higher scores than their younger counterparts and benign causes, respectively. FF Score document that patients with malignant diseases have significantly higher scores than patients with benign diseases.

**Conclusions:** Ileostomy and colostomy patients have a significantly lower QoL than urostomy patients mostly because of its impact on social relations and self-esteem and self-image.

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## Qualidade de vida nos doentes ostomizados – estudo usando o questionário *Stoma-care QoL* – influência de alguns dados clínicos e demográficos na QoL

### R E S U M O

#### Palavras-chave:

Qualidade de vida

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**Introdução:** Em Portugal estima-se que cerca de 20.000 indivíduos sejam portadores de estoma, com todas as alterações associadas que podem comprometer a sua Qualidade de Vida (QdV).

**Objectivos:** Avaliar a QdV de doentes ostomizados de acordo com o sexo, idade, tipo de cirurgia, doença primária, duração e tipo de estoma.

**Materiais e métodos:** Foram incluídos todos os avaliados na consulta de Estomatoterapia entre Janeiro e Maio de 2017. A avaliação da QdV foi efetuada com recurso ao Questionário de QdV *Stoma care*. Avaliaram-se quatro domínios: autoestima e autoimagem (SeSi); relação com família e amigos (FF) relação com sono e cansaço e inseguranças relacionada com funcionamento do dispositivo (DeF).

**Resultados:** Doentes com urostomia apresentaram Scores Total, SeSi e FF, significativamente superior a doentes com colostomia e ileostomia. Relativamente ao score SeSi, os doentes com idade igual ou superior a 70 anos e doença maligna apresentaram scores significativamente maiores que os mais jovens e com doenças benignas, respectivamente. Quanto ao score FF verificou-se que doentes com causas malignas apresentaram scores significativamente superiores aos com causas benignas.

**Conclusões:** Doente ileostomizados e colostomizados apresenta QdV significativamente inferior aos doentes com urostomia, sobretudo devido ao impacto nas relações sociais, auto-estima e auto-imagem.

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## Introduction

A stoma is a surgical opening of an organ that allows its communication with the outside of the body.<sup>1,2</sup> Colostomy, ileostomy and urostomy are the most common types of stomae.<sup>3</sup> These surgical procedures are performed due to malignancy or benign reasons (congenital abnormalities, trauma, obstruction, ischemia or inflammatory diseases) that require feces or urine diversion.<sup>3,4</sup> Most common causes for colostomy, ileostomy and urostomy are, respectively, colorectal cancer, inflammatory bowel disease and bladder cancer.<sup>5-7</sup> Although there are no exact data about the number of people living with a stoma in Portugal some estimates point to around 20,000 individuals.<sup>7</sup>

Besides the risk of the surgical procedure per se, the existence and functioning of the stoma is associated with a number of changes in patients' everyday life. There is a dramatic change in one's body image that can negatively influence its self-esteem and confidence.<sup>3,8</sup> The loss of control over the elimination of feces and urine, the possible leaks from the pouch, the loud flatulence and bad odors are also distressing factors that can deeply compromise social relations and the individual's well-being.<sup>3,5,9</sup> There are also some physiological changes associated with stoma's functioning that can have a negative impact, namely electrolyte disturbances, skin inflammation, para-stomal hernias, stoma necrosis, retraction or prolapse.<sup>3,10,11</sup>

The World Health Organization (WHO) defines Quality of Life (QoL) as the individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.<sup>12</sup> Patients with a stoma face a variety of physical and psychological challenges either because of their disease, surgery or/and the presence of the stoma that can compromise QoL. Assessing their QoL pattern and its determinants is an essential step toward a better understanding of these patients and improvement in the healthcare provided.

The objective of our study was to assess and compare the QoL of a group of patients with a stoma (colostomy, ileostomy and urostomy) using a questionnaire previously validated for the Portuguese population (*Stoma Care QoL Questionnaire*) (*Annex 1*). We also intended to evaluate if some clinical data namely sex, age, type of surgery (urgency or elective), primary disease and stoma duration influenced patients' QoL.

## Material and methods

Patients with a colostomy, ileostomy or urostomy being followed in the Stomatherapy department in Hospital of Braga observed between January 1st and May 30th 2017.

Patients were interviewed by telephone and applied the *Stoma Care QoL* questionnaire previously validated for the Portuguese population.<sup>13</sup> This questionnaire is composed of twenty questions rated in a four-point Likert-scale (never = 4,

rarely=3, sometimes=2 and always=1). The sum of the answers gives a Total Score ranging from 4 to 80 with higher scores meaning better QoL. The questions can be grouped in order to form four domains: self-esteem and self-image (SeSi score; questions 4, 5, 7, 9, 11; range from 4 to 20), relation with family and friends (FF score; questions 12–20; range from 4 to 36), relation with sleep and fatigue (SF score; questions 6, 8, 10; range from 4 to 12) and ostomy device functioning insecurities (DeF score; questions 1–3; range from 4 to 12). Only patients answering all questions were included.

Clinical data were collected from patient's files and included age, sex, primary disease (benign or malignant), context of surgery (elective or emergency), duration (<12 months or  $\geq$ 12 months) and type of stoma (colostomy, ileostomy or urostomy).

Data analysis was performed with IBM® SPSS Statistics 24 software. Normal distribution of numeric variables was assessed with Shapiro–Wilk test. When normality was confirmed mean and standard deviation are presented. In the absence of a normal distribution median is presented as well as non-parametric tests results. Mann–Whitney test was used to compare differences between two independent samples and *p*-values <0.05 were considered significant. For multiple comparisons we used Kruskal–Wallis test (QoL between colostomy, ileostomy and urostomy). In those cases a *p*-value <0.048 was considered significant according to Bonferroni's adjustment.

## Results

### Population

55 patients were enrolled in this study with ages ranging from 34 to 85 years old. There was a general predominance of male patients, slight in colostomy (51.7%) and more pronounced in ileostomy (83.3%) and urostomy (75%). The most common causes for stoma performance were malignant diseases (90.9%). Colostomies and ileostomies were mainly performed because of rectal cancer (69.0% and 55.6%). Only one ileostomy case (5.6%) was caused by ulcerative colitis. Urostomy was performed because of bladder cancer in all cases (100%). This data are described in Table 1.

### QoL – total score

No significant differences were found in general QoL when sex, age, primary disease, type of surgery and stoma duration were analyzed.

Using Kruskal–Wallis test we determined that there was a significant difference between the medians of the three types of stoma,  $\chi^2$  (2, *n*=55)=9.3, *p*=0.01. Pair-wise analysis using Mann–Whitney tests showed that urostomy patients (Mdn=71.5) had significantly higher scores than colostomy (Mdn=58.0), *U*=33.0, *p*=0.002, *r*=0.4 and ileostomy patients (Mdn=59.0), *U*=28.0, *p*=0.014, *r*=0.3. No significant differences were found between colostomy and ileostomy patients' QoL total score. Total Score data are described in Table 2.

**Table 1 – Characteristics of the study population.**

	n (%)
<i>Age, mean</i>	
<70 years	32 (58.2)
$\geq$ 70 years	23 (41.8)
<i>Sex</i>	
Male	36 (65.5)
Female	19 (34.5)
<i>Primary disease</i>	
Malignant	50 (90.9)
Benign	5 (9.1)
<i>Surgery</i>	
Elective	37 (67.3)
Emergency	16 (29.1)
NA	2 (3.6)
<i>Stoma duration</i>	
<12 months	35 (63.6)
$\geq$ 12 months	20 (36.4)
<i>Type of stoma</i>	
Colostomy	29 (52.7)
Ileostomy	18 (32.7)
Urostomy	8 (14.5)
NA, non available data.	

**Table 2 – Comparison of QoL total score according to clinical data.**

	Total score		
	Median	IQR	<i>p</i>
<i>Sex</i>			
Male	62.0	18.5	0.15
Female	57.5	11.0	
<i>Age (years)</i>			
<70	60.0	15.3	0.93
$\geq$ 70	59.0	19.0	
<i>Primary disease</i>			
Malignant	61.0	16.8	0.07
Benign	57.0	21.5	
<i>Surgery</i>			
Elective	60.0	18.0	0.94
Emergency	59.0	7.0	
<i>Stoma duration</i>			
<12 months	58.0	15.8	0.4
$\geq$ 12 months	62.0	19.0	
<i>Type of stoma</i>			
Colostomy	58.0 <sup>a</sup>	13.0	0.01
Ileostomy	59.0 <sup>b</sup>	18.5	
Urostomy	71.5 <sup>a,b</sup>	6.3	

IQR, interquartil range.

<sup>a,b</sup> Significant differences (*p* < 0.05), symbols are used to mark results between different groups.

**Table 3 – Domain analysis (SeSi Score, FF Score, SF Score, and DeF Score) according to sex, age group, primary disease, emergency or elective surgery, stoma duration and type of stoma.**

	SeSi Score			FF Score			SF Score			DeF Score		
	M	IQR	p	M	IQR	p	M	IQR	p	M	IQR	p
Sex												
Male	15.5	7.0	0.12	31.5	7.5	0.56	8.5	6.5	0.06	7.0	4.0	0.37
Female	12.0	5.0		31.0	5.0		6.0	5.0		7.0	3.0	
Age (years)												
<70	13.0 <sup>a</sup>	6.8	0.03	31.0	6.0	0.78	8.5	4.8	0.09	8.0	4.0	0.35
≥70	17.0 <sup>a</sup>	4.5		31.0	7.0		6.0	6.5		6.0	3.0	
Primary disease												
Malignant	15.0 <sup>a</sup>	6.0	0.03	31.5 <sup>a</sup>	5.8	0.02	7.0	6.0	0.92	7.0	3.8	
Benign	11.0 <sup>a</sup>	6.5		28.0 <sup>a</sup>	11.5		8.0	4.5		7.0	5.5	0.54
Surgery												
Elective	15.0	6.0	0.87	31.0	6.5	0.77	7.0	5.5	0.81	7.0	3.5	0.53
Emergency	15.0	6.8		31.5	5.0		6.5	6.3		7.5	3.8	
Stoma duration (months)												
<12	13.0	7.8	0.22	30.5	7.8	0.31	8.5	5.0	0.94	6.5	3.5	0.61
≥12	15.0	6.0		32	5.5		7.0	6.0		7.0	3.5	
Stoma												
Colostomy	14.0 <sup>a</sup>	6.5	<0.01	31.0 <sup>a</sup>	4.0	0.02	6.0	4.5	0.07	7.0	3.5	
Ileostomy	14.5 <sup>b</sup>	6.8		28.0 <sup>b</sup>	9.5		9.5	7.8		6.0	2.5	0.15
Urostomy	18.0 <sup>a,b</sup>	0.8		33.5 <sup>a,b</sup>	3.8		9.5	3.5		9.5	2.8	

M, median; IQR, interquartile range.

<sup>a,b</sup> Results have significant differences ( $p < 0.05$ ), symbols are used to mark results between different variables.

### QoL – SeSi score

Patients aged 70 year old or more (Mdn=17.0) presented significantly higher scores than younger patients (Mdn=13),  $U=239.5$ ,  $p=0.03$ ,  $r=0.3$ . When malignancy was evaluated we found patients with malignant disease (Mdn=15.0) to score significantly higher than patients with benign causes (Mdn=11.0),  $U=50.5$ ,  $p=0.03$ ,  $r=0.3$ . Using Kruskal–Wallis test we determined that means among the three types of stomae were significantly different,  $\chi^2(2, n=55)=11.7$ ,  $p=0.003$ . Pair-wise comparison showed patients with urostomy (Mdn=18) to have significantly higher scores than patients with colostomy (Mdn=14.0),  $U=17.5$ ,  $p<0.001$ ,  $r=0.5$  and ileostomy (Mdn=14.5),  $U=33.5$ ,  $p=0.03$ ,  $r=0.3$ . No significant differences were found between colostomy and ileostomy as well as when sex, type of surgery and stoma duration were analyzed. Table 3 describes SeSi Score according to sex, age group, primary disease, emergency or elective surgery, stoma duration and type of stoma.

### QoL – FF score

Patients with malignant diseases (Mdn=31.5) scored significantly higher than patients with benign diseases (Mdn=28.0),  $U=44.0$ ,  $p=0.02$ ,  $r=0.3$ . Multiple comparison analysis showed significant differences between the three types of stomae,  $\chi^2(2, n=55)=7.8$ ,  $p=0.02$ . Pair-wise comparison once again revealed that urostomy patients (Mdn=33.5) had significantly higher scores than colostomy (Md=31.0),  $U=55.5$ ,  $p=0.02$ ,

$r=0.3$  and ileostomy patients (Mdn=28.0),  $U=29.5$ ,  $p=0.02$ ,  $r=0.3$ ). Colostomy and ileostomy scores did not differ significantly. Table 3 describes FF Score, SF Score, and DeF Score) according to sex, age group, primary disease, emergency or elective surgery, stoma duration and type of stoma.

### QoL – SF score DeF score

We found no differences in median scores according to the demographic and clinical data evaluated (sex, age, primary disease, type of surgery, stoma duration and stoma type). Table 3 describes SF Score, and DeF Score according to sex, age group, primary disease, emergency or elective surgery, stoma duration and type of stoma.

## Discussion

Patients with a stoma face a variety of physical and psychological challenges either because of their disease, surgery and the presence of the stoma that can compromise QoL. Assessing their QoL pattern and its determinants is an essential step toward a better understanding of these patients and improvement in the healthcare provided. In this work we tried to evaluate the influence of some demographic and clinical data in ostomized patients' QoL.

When gender was considered, no significant differences were observed both on total score and domain analysis. A previous study conducted in Germany showed women to be more

affected in physical and overall domains and men to have their QoL more affected in sexual terms.<sup>14</sup> A study with rectal carcinoma patients also found women to have significantly worse values than men on an insomnia scale (from the QLQ-C30).<sup>15</sup> Our results in SF Score are close to significance and may result from the fact that women are more affected physically than men. There are also works stating that female patients tend to have lower scores regarding psychological and social well-being.<sup>16-18</sup> A study conducted in Turkey with 44 patients who underwent abdominoperineal resection also found women to score significantly worse than men in general health perception, role emotion and mental component.<sup>19</sup> We found no significant differences between men and women in the two domains regarding psychological and social well-being (SeSi and FF scores). A study with 2497 patients showed significantly lower general QoL scores for women with colostomy and no difference between gender when small bowel stoma was evaluated.<sup>20</sup> There is some controversial results regarding gender and QoL in ostomized patients and our results seem to be in agreement with previous works stating that gender can influence QoL, however not enough to become a predictive factor.<sup>21,22</sup> Probably a bigger population with a more balanced ratio between men and women could help clarify these data.

We divided our population into two groups according to their age (younger than 70 years old and 70 years old or more). The Total score analysis did not show significant differences according to patients' age group, which is in accordance with previous studies where older patients tended to score as well or higher than younger patients when general perception of QoL was assessed.<sup>5,23,24</sup> We were able to find significant results in the SeSi Score analysis, with older patients scoring higher than their younger counterparts. A previous study of 239 patients with an intestinal stoma showed that younger participants were significantly more likely to be embarrassed compared to the older ones<sup>25</sup> and so it is likely that our results are related to the fact that younger patients tend to value more the impact of body image changes. We must also pay attention to the fact that SeSi score included a question about sexual attractiveness and previous studies found that younger patients usually presented lower scores in sexual terms.<sup>26,27</sup> There is also evidence that when mental component is evaluated younger patients tend to have lower scores than the general population while older patients seem to have similar scores to the general population.<sup>28</sup> Interestingly, some works observed that older patients perform worse on scores evaluating the ability to take care for the stoma, although this fact did not significantly affected their general perception of QoL.<sup>23,29</sup> In our population this tendency was also observed (patients aged 70 years old or more had a slightly lower DeF score) although without significance. It is also documented that 69 years old or younger patients present better scores in the physical domain.<sup>15,26</sup> Once again our results seem to be in agreement (younger patients had higher SF Scores) although without significant results.

There is some evidence that patients who underwent stoma formation because of malignant causes tend to cope better with the presence of their stoma.<sup>8</sup> Our results show patients with malignant causes to have significantly higher scores in questions evaluating Self-esteem and Self-image (SeSi score) and social relations (FF score). Patients with

malignant diseases may experience a variety of symptoms such as pain, constipation, diarrhea, loss of blood in feces or urine, weight loss and physical debilitation. This symptoms and the idea of a life-threatening disease might highlight the importance of function and symptomatic relief, leading to a better coping with body-image changes. It is also likely that this idea could make patients' family and friends to be more supportive and present, thus improving their social support. Despite these results Total score does not differ significantly between patients with benign and malignant diseases which is in agreement with a previous study that found some significant differences in symptomatic parameters but could not find significant results in general QoL assessment.<sup>20</sup> We must take into consideration that our population as a majority of patients with malignant diseases (90%) and results should be interpreted with caution. A more even ration between malignant and benign diseases would allow more reliable conclusions.

The importance of emergent surgery in ostomized patients' QoL remains controversial. There are works describing emergent surgery as a risk factor for complications while others deny it.<sup>30</sup> It is widely accepted that correct stoma marking, surgical construction and careful follow-up are important factors in the prevention of stoma related complications.<sup>10</sup> It has also been proved that instruction by a stomatherapy nurse prior to surgery leads to significantly better results in physical and psychological domains.<sup>16</sup> We expected that in emergent situations where marking and counseling are not always adequately provided and there is a possible higher risk for complications patients would have lower QoL scores. However we found no significant result which is accordance with some studies that could not find significant differences when comparing general QoL between patients who had their stomas marked prior to surgery and those who had not.<sup>16</sup>

Time from surgery has been related with adaption to the stoma and improvement in body image with progressive lower levels of distress and higher levels of acceptance as time passes.<sup>8</sup> We found no significant differences between patients who had their stoma for less than one year and those who had it for one year or more. These data are in agreement with previous works that could not find significant differences when they compared QoL general perception according to stoma's duration.<sup>16</sup>

There are few studies comparing types of stoma and QoL. Although several studies verified that patients with loop ileostomy had more complications than patients with colostomy<sup>11</sup> it seems that there are no significant differences in QoL between the two types of stoma.<sup>20</sup> This study showed no significant differences between patients with colostomy and ileostomy both on general QoL and domain assessment, which seems to be in agreement with the literature. However we must keep in mind the scarcity of studies and that one of the above mentioned included only patients with temporary stoma and the other had as main objective to evaluate the effect of age and not the impact of the type of stoma. Further studies are required in order to allow solid conclusions.

There is a wide variety of studies comparing complications and QoL between different types of urostomy, however we could not find any works comparing urostomy with intestinal

stomae. We found urostomy patients to score significantly higher than colostomy and ileostomy patients on Total score and domains addressing Self-image (SeSi score) and relations with Family and Friends (FF score). This results might be related to the stoma effluent of urostomy to be more tolerable on skin and visually, have less impact on personal hygiene and be more easy to handle in case of a leakage. Intestinal stomae also have the problem of audible flatus that is absent in urostomy. All these factors might lead to less negative impact and social restrain on patients with urostomy, thus leading to better QoL. Results regarding the device functioning were not significantly different among the three types of stoma and that might be explained by the similarity of appliances. We must also keep in mind that all cases of urostomy were performed due to malignant disease and so these results must be considered with caution.

This study is based on a stoma specific questionnaire. The use of such questionnaires has been highlighted by previous studies once there are significant QoL issues related to stoma despite a good global QoL measured by general QoL scales.<sup>21</sup> To our knowledge this is the first time since its validation that Stoma Care QoL questionnaire is used to analyze and compare QoL in ostomized patients in Portugal.

The scarcity of national works does not allow a comparison between centers. A multi-center study would give rise to more solid conclusions and by means of comparison allow a change of experience and mutual learning. In the global scenario comparison between studies is difficult due to the variety of questionnaires used to access QoL.

This work can be criticized for the fact that it is not a prospective study and due to its cross-sectional character conclusions must be considered with caution. It must also be taken into consideration some characteristics of the population, namely the ratio between men and women and

benign and malignant diseases. Other factors that are being considered in some works and could be addressed in the future are the influence of residency, marital status, education and income level, neoadjuvant treatments, comorbidities and presence of metastasis in malignant disease.

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## Conclusion

It is undeniable that quality of life is an increasingly important outcome measure in surgery. Knowing the impact of a surgical procedure in the individuals' quality of life allows both the physician and the patient a more informed and adequate decision.

The presence of a stoma has a negative impact on patients' QoL. Identifying the groups more affected would allow us to address their needs and therefore improve the quality of care offered to these individuals. In this study, ileostomy and colostomy patients have a significantly lower QoL than urostomy patients mostly because of its impact on social relations with family and friends, self-esteem and self-image. The next step would be to understand clearly what differences between intestinal and urinary stomae give rise to these differences. Identifying these characteristics might allow us to define targets and strategies to help our patients to cope better with their stomae. Also, patients with benign disease seem to have more difficulties in social relations because of their stomae and although no impact on general QoL was found we must pay particular attention to this aspect during their follow-up.

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## Conflicts of interest

The authors declare no conflicts of interest.

**Annex I. Stoma care QoL Questionnaire. DeF Score, Ostomy device functioning insecurities; SeSi Score, Self-esteem and Self-image; SF Score, Relation with sleep and fatigue; FF Score, Relation with family and friends.**

Item	Always (1)	Sometimes (2)	Rarely (3)	Never (4)
I become anxious when the pouch is full				DeF score
I worry that the pouch will loosen				
I feel the need to know where the nearest toilet is				
I worry that the pouch may smell				SeSi Score
I worry about noises from the stoma				SeSi Score
I need to rest during the day				SF score
My stoma pouch limits the choice of clothes that I can wear				SeSi Score
I feel tired during the day				SF score
My stoma makes me feel sexually unattractive				SeSi Score
I sleep badly during the night				SF score
I worry that the pouch rustles				SeSi Score
I feel embarrassed about my body because of my stoma				FF Score
It would be difficult for me to stay away from homeovernight				
It is difficult to hide the fact that I wear a pouch				
I worry that my condition is a burden to people close to me				
I avoid close physical contact with my friends				
My stoma makes it difficult for me to be with other people				
I am afraid of meeting new people				
I feel lonely even when I am with other people				
I worry that my family feel awkward around me				

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