

# Quality of Life Regarding People with an Ostomy: Integrative Review about Related Factors

REVIEW

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## Abstract

**Objective:** Analyze the studies which present aspects related to the quality of life of patients with an ostomy.

**Method:** It is about an integrative review in databases of the literature held in the Latin American Literature and Caribbean health sciences, *Medical Literature Analysis and Retrieval System Online*, *Nursing Database*, *PubMed Central*, *Cumulative Index to Nursing and Allied Health Literature*, *Web of Science* and *SciVerse Scopus*. Controlled keywords of the *Medical Subject Headings (MESH)* were used: "Ostomy" and "Quality of life". The additional factors were: scientific articles that measure the QOL of people with an ostomy and/or scientific articles that show at least one aspect which affects the QOL of those people. After the analysis, the final sample was composed of 41 articles that passed through statistical analysis to identify the factors that best associated and correlated to the life quality of patients with an ostomy.

**Results:** International studies with the level of evidence VI were predominant. 40 factors associated with the QOL of people with an ostomy were observed and subdivided into the domains: sociodemographic, clinical, physical, psychological and social.

**Conclusion:** The main factors related to the quality of life of patients with an ostomy were: age, income, gender, change in physical and in sexual function ( $p < 0.001$ ). However, as it is about a review study, it needs the validation of the factors that most stand out in this theme.

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## Keywords

Ostomy; Quality of Life(QOL).

## Introduction

The ostomy is made by a surgical procedure, whose objective is to link organs or bowels with the external environment, when it is needed to divert the normal physiologic way of feeding and elimination, on a temporary or permanent way [1]. The ostomies are named according to its location, being intestinal, classified as colostomy and ileostomy, and being in the bladder, as urostomy. [2].

Even with the current technological advances to minimize the damage coming from the surgery of an ostomy, the patient with this deflection can suffer physical complications related to the loss of the integrity of the body, losing control of the evacuation process, unwilling elimination of gas and odors; and psychological, like the lack of confidence and self-esteem, causing depression. These changes can result on a negative impact on the quality of life (QOL), leading to great difficulties to the adaptive and rehabilitation process of those people [3].

The existence of the ostomy configures a whole new way of life for the patients, because of this, the person with the ostomy has to modify his daily activities, has to dress in a different way, adopt a new diet, transform his life style [4,5]. These factors must be worked in a way to help on the adaptation of the individual in his new reality, considering his limitation and possibilities. Therefore, the health care professional is a fundamental piece on the process of rehabilitation of the patient, contributing to a more humanized, resolute and qualified aid to this public [6,7].

The elimination of unwilling gas and secretion to the ostomy pouch cause the patient to be embarrassed, provoking emotional changes that require adaptation. Furthermore, the presence of the ostomy bag changes the scope on sexuality and the living with other people, making it harder to reestablish or maintain relationships [4].

The QOL of stoma patients is affected by the experiences of life and the techniques that were developed to confront this new condition imposed

with the goal to overcome this limitation and adapt to the biopsychosocial changes [4].

The perception about the QOL is considered to be subjective, with a lot of perspectives, reflecting the individuality of multiple factors. According to the World Health Organization (WHO), there are five domains that define the QOL, those are: physical, psychological, social, economic and spiritual. The QOL can be measured by generic instruments like the *Medical Outcomes Study 36- Item Short-Form Health Survey (SF-36)* and specific like *City of Hope Quality of Life-Ostomy Questionnaire (COH-QOL-OQ)*, being these ones the most used [8].

The information about the QOL of people with an ostomy will provide a vast perception about the aspects that affect it, making the multi professional team to look for more efficient actions for a better support to those people in an integral manner, raising their QOL, added to a better promotion of health and the patient-professional relationship. With these reflections in mind, the current review has as an objective to analyze the most found aspects in the Literature related to QOL of people with an ostomy.

## Method

This research used as method the integrative review of the literature, whose main purpose is to select and group studies that involve a determined theme, and that brings common components, based on scientific knowledge [9].

To accomplish this, the following steps were taken: formulation of the guiding question; the institution of the study subject with determined rules of inclusion and exclusion of the articles; definition of the information that will be extracted during the data gathering; analysis revision of the results; debate about the results, and the final consideration about the research [9].

As a way to conduct the review, the guiding question formulated was: What are the factors that affect the quality of life (QOL) of people with

an ostomy? During the month of March 2015, the survey of Latin American Literature on the electronic database were gathered: Latin American and Caribbean health sciences literature (LILACS), *Medical Literature Analysis and Retrieval System Online (MEDLINE)*, Database of Nursing (BDENF), PubMed Central, *Cumulative Index to Nursing and Allied Health Literature (CINAHL)*, *Web Of Science e Sci-Verse Scopus (SCOPUS)*.

To the survey of those editions the following keywords were used: *Medical Subject Headings (MESH): "Ostomy" and "Quality of life"*. Which were prospected together using the Boolean operator *AND*.

To choose the sample the following rules of inclusion were adopted: scientific articles that measure the QOL of people with an ostomy and/or scientific articles that present at least one aspect that affects the QOL of those people. To do so, the limit of time and the language were not considered and the chosen articles were classified based on the evidence levels.

This selection was assembled using seven levels: Level I – resulting evidences of systematic reviews or meta-analysis of relevant clinical trials. Level II - evidence from at least one clinical trial that is well outlined, controlled and randomized. Level III – clinical trials well outlined that are not randomized. Level IV – Well outlined studies of cohort and case-control. Level V – systematic review of the descriptive and qualitative studies. Level VI – evidence from only one descriptive or qualitative study. Level VII – stan-

dpoint of authorities or reports from a committee of specialists. The evidences of the Levels I and II are considered strong; from III to V, are moderate evidences and VI and VII, weak evidences [10].

The publications in format of editorial, letter to the editor or literature revision were excluded.

On the statistical analysis of the factors related to the QOL, the test of fisher was used to verify the association between these factors with their respective domains and the Spearman's correlation coefficient ( $r \geq 0.750$  = strong; from 0.500 to 0.749 = moderate;  $\leq 0.499$  = weak), to verify the correlation between the domains and their corresponding variables with the level of statistic importance of  $p - \text{value} \leq 0.05$ .

The **Table 1** presents the steps to obtain the final sample of this study.

The articles chosen for the final sample of this literature review, after the full reading, had their data grouped according to the instruments used to measure the QOL of people with an ostomy, as well as important aspects which affect it.

## Results

The final sample counted with 41 publications chosen between the years of 2004 and 2014, there were mainly international studies (82.9%), with qualitative approach (80.5%) and with level VI of evidence (56.1%) (**Table 2**).

40 aspects related to the QOL were detected on the analyzed studies, being grouped in five

**Table 1.** Distribution of the articles found and chosen.

Articles/Base	LILACS	MEDLINE	CINAHL	SCOPUS	PUBMED	Web of Science	Total
Found	16	73	214	2,470	212	199	3184
Duplicated	4	8	5	0	3	3	23
Excluded	5	65	211	2435	210	198	3124
Chosen for full Reading	7	22	26	35	11	11	113
Included Studies	2	8	2	27	1	1	41

Source: Self-research.

**Table 2.** Distribution of the studies regarding the periodic, publish year, Location where the study was made, approach and level of evidence.

Reference	Title of the journal	Publish Year	Location where the study was made	Approach	Evidence Level
11	Indian J Palliat Care	2012	Iran	Quantitative	IV
12	Eur j gastroenterol hepatol	2010	Denmark	Quantitative	III
13	Health qual life outcomes	2014	Italy	Qualitative	IV
14	Support care cancer	2014	Australia	Quantitative	IV
15	Psycho-oncol	2013	USA	Both	IV
16	Psycho-oncol	2014	Netherlands	Quantitative	IV
17	Oncol Nurs Forum	2011	USA	Both	IV
18	J clin Oncol	2009	USA	Quantitative	III
19	Curr med res opin	2008	USA	Both	IV
20	Dis Colon Rectum	2010	USA	Quantitative	IV
21	J Wound Ostomy Continence Nurs	2010	USA	Quantitative	IV
22	J Wound Ostomy Continence Nurs	2009	USA	Both	IV
23	Women Health	2009	USA	Qualitative	IV
24	Med Care	2011	USA	Quantitative	IV
25	J Wound Ostomy Continence Nurs	2013	USA	Both	IV
26	J Clin Sleep Med	2009	USA	Both	VI
27	Colorectal Dis	2012	Sweden	Quantitative	VI
28	Indian J Surg	2014	India	Quantitative	VI
29	J Coloproctol	2013	Brazil	Quantitative	VI
30	Asian Biomedicine	2012	Thailand	Quantitative	VI
31	World J Surg Oncol	2014	China	Quantitative	VI
32	Psychooncology	2011	Netherlands	Quantitative	IV
33	Cirugía y Cirujanos	2011	Mexico	Quantitative	VI
34	J Coloproctol	2012	Brazil	Quantitative	VI
35	J Coloproctol	2014	Brazil	Quantitative	VI
36	Rev Inst Ciência e Saúde	2007	Brazil	Quantitative	VI
37	PLoS One	2014	Denmark	Quantitative	VI
38	Indian J Palliat Care	2009	India	Quantitative	VI
39	Health Qual Life Outcomes	2013	Multicente - Internacional	Quantitative	VI
40	Rev. Latino-Am. Enfermagem	2004	Brazil	Quantitative	VI
41	African Health Sciences	2014	China	Quantitative	VI
42	Colorectal Dis	2009	Italy	Quantitative	VI
43	Rev bras colo-proctol	2010	Brazil	Quantitative	VI
44	Dis Colon Rectum	2009	Netherlands	Quantitative	VI
45	Am J Surg	2007	USA	Quantitative	III
46	ANZ J Surg	2007	New Zealand	Quantitative	IV
47	Ostomy Wound Manage	2006	USA	Quantitative	VI
48	Health Qual Life Outcomes	2012	Iran	Quantitative	VI
49	J Surg Res	2007	USA	Quantitative	VI
50	Qual Life Res	2009	USA	Quantitative	VI
51	J Coloproctol	2014	Brazil	Quantitative	VI

Source: Self-research.

domains: sociodemographic, clinical, physical, psychological and social. It was possible to see that 26.9% of the factors belonged to the sociodemographic; 46.3% to the clinical; 53.7% to the physical; 46.3% to the psychological and

53.7% to the social. Aspects like the change on sexual and physical function were more relevant in articles that involved QOL of people with an ostomy. **Table 3** show details on the presentation of those data.

**Table 3.** Distribution of the studies in relation to the domains pertinent to the aspects related to QOL of people with an ostomy.

Domains	Aspects related to Quality of life	Reference	n (%)	
Sociodemographic	Age	24, 31, 38, 42, 46	5 (12.2)	
	Income	24, 29, 34, 35, 50	5 (12.2)	
	Gender	18, 31, 38, 48	4 (9.8)	
	Insufficient education	31, 38	2 (4.9)	
	Marital status	31	1 (2.4)	
Clinical	Complications with an ostomy.	20, 24, 25, 28, 41, 42, 44	7 (17.1)	
	Problems with peristomal skin.	12, 25, 30, 40	4 (9.8)	
	Presence of comorbidities.	24, 27, 30, 44	4 (9.8)	
	Time of the ostomy	11, 34, 39, 51	4 (9.8)	
	Reason to do the ostomy surgery.	11, 19, 27, 32	4 (9.8)	
	Hospitalizations.	24	1 (2.4)	
	Obesity.	30, 43	2 (4.9)	
	Place of the ostomy.	11	1 (2.4)	
	Leakings.	12, 33	2 (4.9)	
	Type of the ostomy.	12	1 (2.4)	
	Irrigation of the stomy.	25	1 (2.4)	
	physical	Physical fuction changes.	16, 18, 28, 29, 34, 36, 37, 39, 40, 41, 45, 47, 49	13 (31.7)
		Pain and discomfort.	28, 29, 37, 40, 41, 47, 49	7 (17.1)
Daily activities restrictions.		13, 25, 29, 34, 35, 40	6 (14.6)	
Fatigue.		26, 27, 39, 41, 49	5 (12.2)	
Labor capacity.		29, 31, 38, 40	4 (9.8)	
Sleep and rest pattern changes.		13, 17, 26, 29	4 (9.8)	
Odor		13, 25, 27, 28, 41	5 (12.2)	
Food Pattern changes.		25, 39	2 (4.9)	
Gas.		25, 28, 49	3 (7.3)	

Domains	Aspects related to Quality of life	Reference	n (%)	
Psychological	Depression.	11, 16, 24, 34, 47, 49	6 (14.6)	
	Psychological changes.	18, 34, 36, 39, 45, 47	6 (14.6)	
	Mental health.	16, 28, 37, 45, 47	5 (12.2)	
	Anxiety.	16, 27, 28, 34, 49	5 (12.2)	
	Psicosocial adjustment.	22, 47	2 (4.9)	
	Self-esteem.	35	1 (2.4)	
	Change on apparel.	11, 25	2 (4.9)	
	Disorder on the body image.	14, 17, 41, 49	4 (9.8)	
	Social	Sexual function changes.	11, 13, 14, 16, 17, 21, 23, 31, 33, 34, 36, 44, 48, 49	14 (34.1)
Social activities changes.		13, 18, 34, 35, 36, 43, 45, 47, 49	9 (22.0)	
Decrease on participation and opportunities of leisure.		29, 35	2 (4.9)	
Decrease on independency.		13, 35, 49	3 (7.3)	
Living place.		29, 34, 36	3 (7.3)	
Spiritual welfare.		11, 15, 34, 40	4 (9.8)	
Decrease on opportunities to acquire new skills.		29, 36	2 (4.9)	
Source: Self-research.				

On **Table 4**, the aspects related to QOL changed into variables seeking to identify their importance inside the domains. It was possible to see that there were twenty variables with statistical importance among them, being three on the sociodemographic aspect (age, income and gender), five on the clinical aspect (complication, peristomal skin, comorbidity, time of the ostomy and reason of the ostomy), five on the physical aspect (physical function change, pain and discomfort, restrictions, fatigue and

**Table 4.** Association among sociodemographic, clinical, physical, psychological and social aspects with their respective domains.

Aspects	n(%)	n(%)	p-value
	Absent	Present	
<b>Sociodemographic Domain</b>			
Age	36 (87.8)	5 (12.2)	<0.001*
Income	36 (87.8)	5 (12.2)	0.001*
Gender	37 (90.2)	4 (9.8)	0.004*
Level of education	39 (95.1)	2 (4.9)	0.073
Marital status	40 (97.6)	1 (2.4)	0.279
<b>Clinical Domain</b>			
Complications	34 (82.9)	7 (17.1)	0.002*
Peristomal Skin	37 (90.2)	4 (9.8)	0.039*
Comorbidity	37 (90.2)	4 (9.8)	0.039*
Time of the ostomy	37 (90.2)	4 (9.8)	0.039*
Reason of the ostomy	37 (90.2)	4 (9.8)	0.039*
Hospitalizations	40 (97.6)	1 (2.4)	0.21
Obesity	39 (95.1)	2 (4.9)	0.21
Location	40 (97.6)	1 (2.4)	0.465
Leaking	39 (95.1)	2 (4.9)	0.21
Type of ostomy	40 (97.6)	1 (2.4)	0.465
Ostomy Irrigation	40 (97.6)	1 (2.4)	0.465
<b>Physical Domain</b>			
Physical function change	28 (68.3)	13 (31.7)	<0.001*
Pain e discomfort	34 (82.9)	7 (17.1)	0.004*
Restrictions	35 (85.4)	6 (14.6)	0.021*
Fatigue	36 (87.8)	5 (12.2)	0.048*
Labor capacity	37 (90.2)	4 (9.8)	0.108
Sleep change	37 (90.2)	4 (9.8)	0.108
Odor	36 (87.8)	5 (12.2)	0.048*
Food pattern change	39 (95.1)	2 (4.9)	0.488
Gas	38 (92.7)	3 (7.3)	0.233
<b>Psychological</b>			
Depression	35 (85.4)	6 (14.6)	0.004*
Psychological change	35 (85.4)	6 (14.6)	0.009*
Mental health	36 (87.8)	5 (12.2)	0.009*
Anxiety	36 (87.8)	5 (12.2)	0.021*
Psicosocial adjustment	39 (95.1)	2 (4.9)	0.233
Self-esteem	40 (97.6)	1 (2.4)	0.488
Apparel	39 (95.1)	2 (4.9)	0.233
Body image	37 (90.2)	4 (9.8)	0.048*

Aspects	n(%)	n(%)	p-value
	Absent	Present	
<b>Social Domain</b>			
Sexual function	27 (65.9)	14 (34.1)	<0.001*
Social Activities	32 (78.0)	9 (22.0)	0.001*
Leisure	39 (95.1)	2 (4.9)	0.491
Independency	38 (92.7)	3 (7.3)	0.236
Social enviroment	38 (92.7)	3 (7.3)	0.236
Spiritual welfare	37 (90.2)	4 (9.8)	0.111
New skills	39 (95.1)	2 (4.9)	0.491
<b>Source:</b> Self-research. *: Fisher exact test.			

odor), five on the psychological factor (depression, psychological change, mental health, anxiety and body image) and two on the social aspect (sexual function and social activities).

When all the variables are correlated with their respective domains, it is possible to see the correlation from weak to moderate, positive and statistically significant for the physical, psychological and social domains (**Table 5**).

At the end of the statistical analysis, a logical regression on the domains with a significant correlation was made and it was possible to see that among them there is a precision of 78.4%, being the physical domain the one that contributed most for that followed by the social and psychological, on that order.

**Table 5.** Correlation among the sociodemographic, clinical, physical, psychological e social domain with the total of aspects that are in the studies.

Domains	Total Scale	
	Correlation coefficient	p-value
Sociodemographic	0.147	0.346
Clinical	0.138	0.377
Physical	0.739*	<0.001
Psychological	0.610*	<0.001
Social	0.423*	0.005
<b>Source:</b> Self-research. *: The correlation is statistically significant.		

## Discussion

On the sociodemographic domain, it is possible to see that the variables like age, income and gender, were the most frequent when the QOL of people with an ostomy is studied. Brazilian studies show the prevalence on women, whose age is above 50 and an average monthly income of one or two minimum wages [52-54].

About the gender it has been observed that women tend to have a lower quality of life compared to the opposite sex, since, the body image changes [55], the deprivation of the household tasks and the fear for rejection increases the social isolation, hinders the adaptation, decreases the self-esteem and the quality of life. The struggle and the difficulty to adapt are overly reported by women, while men seem not to show too much concern about these questions. Thereby, women are more likely to seek for emotional support and develop recovery strategies [17].

In relation to the family income, evidences prove that the high cost of the products and materials destined for ostomy care, establish lower level of quality of life [56]. After the ostomy is made, new expenses will be needed to acquire collector's bag and aids, the deprivation of those assets due to low economic level hinders the adaptive process and decrease the welfare levels [57].

Relating the age-group, it was found a study that demonstrate the association of the low QOL in young people in the case of their emotional state, perspective of the future and economic situation, in contrast, it was possible to observe the relation of the lower QOL in elder people in terms of physical function [31].

The process of aging by its own, brings to the individual body, physical and psychological modifications that hinders the realization of tasks and restricts the independency of this elder, this way, followed by this process, there were signs of the disengagement of labor activities and a distance on social interaction [58]. Younger people would

have a bigger adaptive capacity and self-care than elders, since, people with more advanced age need caretakers to handle the ostomy [30].

On the other hand, the young adult when unable to accomplish his daily and labor activities, faces obstacles like the impossibility to maintain the habitual financial status, because they are the ones that sustain their families, so, the decreasing in the levels of self-esteem and changes on the quality of life are seen among them [59].

Regarding the clinical domain, it was seen that complications with the ostomy, skin issues, comorbidities –among them the obesity– time of the ostomy and the reason for the ostomy were the most statistically important variables. Among the most common reasons to do the ostomy surgery are the neoplasia that normally end in definitive colostomies [52-54].

The person with an ostomy can develop complications like, necrosis, retraction, prolapse, stenosis, fistula, paracolostomy hernia and abscesses, due to a bad position of the ostomy on the abdominal wall [60] and the lack of orientations regarding the handle of the ostomy, on the pre-surgery period [61]. There are also complications on the peristomal skin, with emphasis on the dermatitis, that appear due to the inadequate adjustment of the device, leading to a constant leaking of effluent that because of the acidity causes the dermatitis and skin issues surrounding the ostomy [60]. It should be highlighted the importance of the orientations provided by the multi professional team about the self-care, aiming the minimization of the occurrence of those complications that makes it harder to adapt and reflect negatively on the QOL of the individuals with an ostomy [56].

About the presence of comorbidities, it was seen that the mortality after colorectal operations increased significantly in the presence of comorbidities, as well as the occurrence of surgical complications [62]. Another study shows that the number of days of hospitalization and rate of comorbidities has a

negative effect to the QOL of the patients when evaluated by the SF – 6D instrument [24].

The time of the ostomy affect the adaptation of the patient. Patients reported the need of a minimum period of six months to learn how to handle the self-care and have an adequate diet [11]. It is seen that patients with a definitive ostomy accept better their condition, since, they know the ostomy will be there for their whole life, having nothing else to do, but to adapt to this new situation [4,36,63], granting a better adaption and improvement on the QOL. However, those results differ from the ones found in another study, where, patients with a temporary ostomy handle life like something really significant and show a better score of QOL when compared to definitive ostomy bearers [34].

Concerning the reason, the cancer was the major diagnosis that caused the ostomy surgery, the levels of welfare and quality of life can be found low on the patients with that diagnosis, especially for the fear of the recurrence of a tumor [7, 39], fear of death and suffering.

Related to the physical domain, aspects like change in the physical function, pain and discomfort, restrictions on daily tasks, fatigue and odor contributed to the worse score of quality of life on this domain.

Modification on the physical function related to body changes caused by surgical procedure and the new condition makes the individual with an ostomy feel different. The physiological gastrointestinal modifications and the interaction with the ostomy bag, caused significant changes on the capacity to do his daily and leisure activities, requiring a lot of times, help on activities like daily hygiene, handle and swapping of ostomy bags, and attention to the ostomy, aspects related to the worst quality of life to those people. This fact makes, a lot of time, patients feel dependent on other people and less productive compared to before the surgery [64, 65].

A study demonstrated the prevalence of fatigue in patients with colorectal cancer as symptom that

interfere directly on the quality of life of the individual [66]. Combined to that, the presence of gas, odor, incontinence and diarrhea are considered factors that interfere on the quality of life, because, at any moment, the stools can fill the ostomy bag, occurring on a leaking and embarrassment leading him to social isolation [67].

Aspects associated to the psychological domain were identified, like: depression, psychological changes, mental health, anxiety and body image associated to the worse quality of life of people with an ostomy. When the individual is told about the diagnosis and the need of surgical intervention that will result in an ostomy he goes through a period of hard acceptance. It puts people under a threat to their life project and their reality, with a big risk of rupture of their identity [68]. The emotional state of the patient is shown in suffering, and this, a lot of times express feelings like depression, loneliness, suicidal thoughts, in addition to rage, not accepting his condition, anxiety and denial [65, 69].

Added to this, those people still have changes on their self-esteem, caused by the body image modification, both in the representation that he has of his body, as the prejudice coming from other people that sees the ostomy and by the unwilling elimination of gas, generating odors and sadness as they feel different from other individuals [70, 71].

Therefore, the important role played by the health professionals must be considered, when dealing with the body image changes and the representation of the loss of the sphincter control, in order to facilitate the process of acceptance of his actual condition, promote knowledge and self-esteem, demystifying the stigma created and positively influencing his social reinsertion [3].

Factors on the domain that involves social matters were observed, like: the changes in the sexual function and in the social activities as the most important variables. It is a fact that about the sexuality, people with an ostomy, especially the ones that recently made the surgery, can experience chan-

ges due to psychological and physiological factors, which difficult a satisfactory sexual activity. Among them is the anxiety of fear about its capacity of performing the sexual act, the attractiveness of his body is disturbed, there is the possibility of the unpleasant odor and the lack of confidence on the ostomy bag, in order to provide safety [72].

Concerning the social life, people with an ostomy present difficulties and/or limitations on doing activities that they used to do before the ostomy. Club trips, bus travels and practice of sports are now restricted, due to the insecurity related to the ostomy bag that requires specific care [73].

## Conclusion

The present review made possible to analyze the studies that present factors related to QOL of patients with an ostomy. International studies with low level of evidence predominated. Factors related to QOL were observed, with emphasis on age, income, gender, physical and sexual function changes ( $p < 0.001$ ), being the physical, psychological and social domains the ones that significantly correlated with their respective variables.

However, it's important to highlight that this is a review study and it needs a better justified validation about the real factors related to the quality of life of people with an ostomy, since, it's about a subjective, non-consensual and multifactorial theme.

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