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'SOCIAL AND PHYSICAL FACTORS & THEIR ASSOCIATION WITH QUALITY OF LIFE AMONG STOMA PATIENTS IN PAKISTAN'

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ABSTRACT

Background: The definition of health stated by WHO does not merely mean the absence of disease. Applying this concept among the patients who have undergone stoma surgeries is an ideal state to fulfill the health criteria. Stoma surgeries have helped to improve the pathological condition affecting the patients but the existence of the stoma itself could cause various physical and social restrictions which could affect the quality of life of such patients and thus the criteria of health could not be met appropriately. The aim of this study was to identify the physical and social factors contributing towards the quality of life among stoma patients.

Methods: This cross sectional study included ninety seven in-patients who had abdominal surgery and had stoma bag attached between January 2013 and March 2014 at surgical unit III of Civil Hospital Karachi (CHK). A structured interview questionnaire was constructed and patients' responses regarding quality of life after stoma use were recorded by a trained surgeon. Data were analyzed by using Chi square test and logistic regression through SPSS version 16.0.

Results: Thirty two percent of patients (n = 31) reported having a low quality of life due to stoma bag. Chi square test results indicate that duration of stoma implantation among patients was significantly associated with patients' wellbeing (χ^2 = 4.36, p value = 0.037). Patients who had double barrel type of stoma were nearly 4 times more likely to have low quality of life as compared to patients who had loop type of stoma (OR = 3.96, 95% CI = 1.21 – 12.94, p value = 0.022). Multivariate analysis, after adjusting for all covariates reveals that patients who had stoma bag attached for more than six months were significantly less likely to experience low quality of life (OR = 0.30, 95% CI = 0.10 – 0.89, p value = 0.029).

Conclusion: In thisstudy most of the stoma patients were within the criteria of good quality of life. It showed a significant association with the duration of stoma and quality of life, but still there is a requirement for more detailed studies within such patients with alarger sample size which could include patients of different socio economic status as well. More research would help to project strategies which would be beneficial for stoma patients towards leading a better

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INTRODUCTION

Stoma formation has become one of the most major advancements in surgical sciences [1]. A stoma has become a necessity in patients suffering withsevere abdominal pathologies (blunt trauma,inflammatory bowel disease, colon cancer, enteric perforation, penetrating injuries, abdominal tuberculosis, diverticulitis and intestinal obstruction), due to which the effected organ becomes restricted towards its normal functionality and causes disturbances for the organ to perform its normal physiological and anatomical functions[2] [3].

Some patients might require the stoma for lifelong duration and some might require it for a temporary period [4] [5].The stoma acts as an opening from which the waste materials of the body (feces, urine) come out and are collected in a stoma bag[6]. This stoma may have some pathologicalcomplications (skin problems, diarrhea related to stoma, retraction and prolapse),& may simultaneously also affects the patients physical, social and mental capabilities that the patient might be performing normally before the stoma surgery [3].

The state of health as explained by WHO definition is '*A state of complete physical, mental, spiritual and social well-being of an individual and not merely the absence of disease or infirmity*'[7]**.** Keeping in view this WHO definition of health, stoma patients have been treated for the pathology but due to the stoma itself their social and mental health could be compromised. A stoma formation could affect negatively towards the quality of life of patients. Factors that could lead to such an instability in the physical and social lifestyle of a stoma patient could include difficulty going to work, diminished sexual activity, physical appearance of the body and non-interactionwith relatives and family members due to embarrassment [8].

It has been shown that, in stoma patients the physical change has a significant effect on the patient, which could be social or emotional [9]. Reflecting on the WHO health definition it is important for a health care provider to counsel stomapatients about thepostoperative effects due to stoma and the lifestyle changes that a patient might have to adopt due to the it. This will help the patient to live a healthy life as per the WHO definition and would not be merely the absence of a disease.

Patients with stoma have to take great care of the stoma bag. The management of the stoma bag is one of the principle indicators which couldhavea direct effect towards the quality of life (physical, psychological, social) of the stoma patient. If the patient is able to manage the stoma bag appropriately and independently,it helps to build confidence to the patients, due to which the rest of their daily tasks and social interactions could be completed without any hesitation [10] [11].

There has notbeen much research to seek an evidence of association between the physical and social effects related with a stoma bag in stoma patients within Pakistan. It has been seen that abdominal surgeries which end up in stoma formation are on the rise due to the increase in abdominal pathologies,hence, there is a need to investigate and seek an association into the factors that affect the physical and social lifestyle of stoma patients. This study will be looking to find an association between the physical and social factors which could cause a restriction in the quality of life among stoma patients in Pakistan, and also if there is a relation between the duration of the stoma bag with the quality of life of stoma patients.

MATERIALS AND METHODS

Study participants

A convenience sample of hundred patients was used for this study, out of which ninety seven completed the survey, so the final sample used in the study was ninety seven. This cross sectional study was conducted at the colorectal unit of the Civil Hospital Karachi (CHK). It is a tertiary health center catering to people not only from Karachi but also from other cities of Sindh and Baluchistan. A high patient turnover rate is received by five medical units, six surgical units and 3 gynecology units of the CHK [12].

Patients of either gender, aged 11 to 80, who underwent abdominal surgery and had stoma formed at colorectal unit of Civil Hospital Karachi, between January 2013 and March 2014were included in the study. Patients with physical or psychological disabilities were excluded from the study.

Data Collection

A trained surgeon interviewed the patients after obtaining their informed consent, during the routine checkup at surgical ward. It took the interviewer about 10 – 15 minutes to obtain complete information from each patient.

A structured questionnaire was developed by considering all important factors related to quality of life among patients having stoma. The questionnaire comprised of sixteen questions. Patients' demographic data such as gender, age in years, and disease characteristics such as type of stoma; type of disease; duration of stoma were recorded. The interviewer focused on questions which were directly related to the physical and social wellbeing of patients after stoma. These questions recorded responses of the patients as yes or no.

Statistical analysis

Demographic data such as gender (male and female); age (categorized into two classes, $\leq$30 years and $>$30 years); and disease characteristicssuch as type of stoma (loop, double barrel, and end); type of disease (TB, malignancy, typhoid perforation and other pathology); and duration of stoma

(categorized into two classes, ≤6 months and >6 months) were treated as independent variables. Responses which were related to patients' wellbeing were assigned scores (no = 0, yes = 1). These scores were added up so that patients' quality of life could be quantified and considered as a dependent variable. It ranged from zero to nine and cutoff point was 07. Scores less than or equal to seven were considered as "high quality of life" and scores equal to eight or higher were considered as "low quality of life". Descriptive analysis involved frequency distributions and percentages of all the demographics, disease related characteristics and responses regarding patients' physical and social wellbeing. Inferential analysis involved Chi square tests were applied to check significant association between categorical variables. Univar ate and multivariate logistic regression analyses were also carried out to check the odds ratios of patients' lower quality of life by other independent factors. All test results having p values less than or equal to 0.05 level of significance were considered statistically significant. Statistical Package for Social Sciences (SPSS, version 16.0) was used for analysis.

RESULTS

Baseline characteristics of stoma patients

The response rate for the study was 97% (n = 100). There were 49.5% (n = 48) males and 50.5% (n = 49) females. Mean age of patients was 33.56 years (SD ±14.88 years). More than half (56.7%, n = 55) of patients were less than thirty years, of age. The type of stoma appliances used by patients were loop (50.5%, n = 49), double barrel (16.5%, n = 16) and end (33%, n = 32). Nearly 31% (n = 30) of patients had TB, 14.4% (n = 14) had malignancy and 20.6% (n = 20) had typhoid perforation. Majority of patients (66%, n = 64) had been using stoma bag for less than six months. (See Table 1)

Responses of stoma patients about their physical and social wellbeing

Responses of the patients regarding their physical well-being after stoma use indicate that 77.3% (n = 75) of patients had inadequate sleep at night. It was reported that approximately three quarter of patients felt tired during the day (74.2%, n = 72) and needed to rest (75.3%, n = 73). Patients' perception about their social wellbeing indicate that, 74.2% (n = 72) of patients felt embarrassed about their body due to attached pouch and 73.2% (n = 71) of patients found it difficult to hide their altered body image. (See Table 2)

Factors associated with patients' quality of life

Overall, thirty two percent of patients (n = 31) reported having low quality of life. Patients who were females (34.7%, n = 17); had age less than thirty years (36.4%, n = 20); used double barrel type of stoma (56.2%, n = 9); had TB (40%, n = 12); and had been using stoma pouch for less than six months (39.1%, n = 25) had a lesser quality of life as compared to those who were males; aged more than thirty years; used loop or end type of stoma; had malignancy or typhoid perforation; and spent more than six months

TABLE 1
BASELINE CHARACTERISTICS OF STOMA PATIENTS (N = 97)

Characteristics	n	(%)
Gender		
Male	48	49.5
Female	49	50.5
Age (years)		
≤ 30	55	56.7
? 30	42	43.3
Type of Stoma		
Loop	49	50.5
Double barrel	16	16.5
End	32	33.0
Type of Disease		
Primary Pathology TB	30	30.9
Malignancy	14	14.4
Typhoid Perforation	20	20.6
Any Other Pathology	33	34.0
Duration of Stoma		
≤ 6 Months	64	66.0
? 6 Months	33	34.0

TABLE 2
RESPONSES OF STOMA PATIENTS ABOUT THEIR PHYSICAL AND SOCIAL WELL BEING

Physical wellbeing	**n**	**%**
I need to rest during the day		
No	24	24.7
Yes	73	75.3
I don' t like to go to work		
No	46	47.4
Yes	51	52.6
My stoma pouch limits the choice of Clothes that I can wear		
No	36	37.1
Yes	61	62.9
I feel tired during the day		
No	25	25.8
Yes	72	74.2
I sleep badly during the night		
No	22	22.7
Yes	75	77.3
Social wellbeing		
My stoma makes me feel sexually unattractive		
No	48	49.5
Yes	49	50.5
I feel embarrassed about my body because of my stoma		
No	25	25.8
Yes	72	74.2
It is difficult to hide that I wear a pouch		
No	26	26.8
Yes	71	73.2
I feel lonely even if I am with other people		
No	43	44.3
Yes	54	55.7

with stoma pouch.

Chi square tests' results also indicate that duration of stoma among patients was significantly associated with patients' wellbeing (χ^2 = 4.36, P value = 0.037), whereas no significant association were observed between patients' quality of life and other demographic characteristics. (See Table 3)

Logistic regression analysis for lower quality of life

Univariate logistic regression analysis was carried out to identify the factors which were significantly associated with patients' lower quality of life. It was noted that patients who had double barrel type of stoma were nearly 4 times more likely to have low quality of life as compared to patients who had loop type of stoma (OR = 3.96, 95% CI = 1.21 – 12.94, P value = 0.022); and patients who had been using stoma pouch for more than six months were less likely to spend life of lower quality (OR = 0.35, 95% CI = 0.12 – 0.96, P value = 0.041). This became more evident after adjusting for covariates including: age, gender, and type of stoma, type of disease and duration of stoma. Multivariate analysis reports that patients who had stoma bag attached for more than six months were 70% less likely to experience low quality of life (OR = 0.30, 95% CI = 0.10 – 0.89, P value = 0.029). (See Table 4)

DISCUSSION

The results of this study showed that approximately two third of the stoma patients have a good quality of life with the stoma bag, irrespective of the duration of the stoma bag.It has been seen that patients with stoma bags suffer a lot of physical and social hindrances after a stoma, which could affect their quality of life[13].A study done by *Makela et al*gave similar figures as our study, which also stated that two-thirds of the stoma patients were experiencing good quality of life [14]. *Nugent et al*study also supported that most patients with stomaswere handling the change in lifestyle (physical, social and mental) due to the stoma bag very well [15].

Pomazkin highlighted that in older age groups the quality

TABLE 3
FACTORS ASSOCIATED WITH PATIENTS' QUALITY OF LIFE

Characteristics	Total	High Quality (n = 66)		Low Quality (n = 31)		*p value
		n	%	n	%	
Gender						
Male	48	34	70.8	14	29.2	0.559
Female	49	32	65.3	17	34.7	
Age (years)						
≤ 30	55	35	63.6	20	36.4	0.287
? 30	42	31	73.8	11	26.2	
Type of Stoma						
Loop	49	37	75.5	12	24.5	0.061
Double barrel	16	07	43.8	09	56.2	
End	32	22	68.8	10	31.2	
Type of Disease						
Primary Pathology TB	30	18	60.0	12	40.0	0.641
Malignancy	14	11	78.6	03	21.4	
Typhoid Perforation	20	14	70.0	06	30.0	
Any Other Pathology	33	23	69.7	10	30.3	
Duration of Stoma						
≤ 6 Months	64	39	60.9	25	39.1	0.037
? 6 Months	33	27	81.8	06	18.2	

*p-value has been calculated using Chi square test

TABLE 4
LOGISTIC REGRESSION ANALYSIS FOR LOWER QUALITY OF LIFE

Characteristics	Univariate analysis		Multivariate analysis	
	OR[a] (95% CI)	p value	OR[b] (95% CI)	p value
Gender				
Male	1		1	
Female	1.29 (0.55 - 3.04)	0.560	1.26 (0.47 - 3.38)	0.641
Age (years)				
≤ 30	1		1	
? 30	0.62 (0.26 - 1.49)	0.289	0.67 (0.23 - 1.97)	0.464
Type of Stoma				
Loop	1		1	
Double barrel	3.96 (1.21 - 12.94)	0.022	3.90 (0.92 - 16.58)	0.066
End	1.40 (0.52 - 3.78)	0.505	1.17 (0.37 - 3.67)	0.783
Type of Disease				
Primary Pathology TB	1		1	
Malignancy	0.41 (0.09 - 1.78)	0.234	0.78 (0.12 - 5.15)	0.792
Typhoid Perforation	0.64 (0.19 - 2.14)	0.472	1.34 (0.29 - 5.97)	0.706
Any Other Pathology	0.65 (0.23 - 1.85)	0.421	1.23 (0.32 - 4.76)	0.769
Duration of Stoma				
≤ 6 Months	1		1	
? 6 Months	0.35 (0.12 - 0.96)	0.041	0.30 (0.10 - 0.89)	0.029

OR[a] = unadjusted odds ratio, OR[b] = odds ratio adjusted by all independent variables, CI = confidence interval.

of life was low as compared to patients of lesser age group[16]. In contrast to this, our study indicates that the stoma patients of higher age groups had a better physical and social quality of life as compared to stoma patients of lesser age groups. Another similar study supported *Pomazkin's* study and indicated that older people were more prone to a lesser physical and social lifestyle against younger age people with stoma bags[17]. This could be true due to the fact that older people do get weak and need support managing the stoma bag which could lead them towards a low physical and social quality of life. This signifies that a more detailed study to seek an association of age and quality of life among stoma patients is needed.

The physical and social factors which were looked upon in this study showed that the majority of the stoma patients were having difficulty sleeping at night, felt tired during the day which led them towards needing rest during day time andpatients were socially embarrassed due to their pouch since it affected their way of clothing as well. All these physical and social factors lead the patients towards a negative quality of life. Other studies have also shown that these physical and social factors play an important role in stoma patients towards their quality of life and managing these factors appropriately with pre-operative counseling and post-operative support and counseling makes things easier for stoma patients to cope with the hindrances and adjust them within their lifestyle[5][8][18]. This shows that stoma patients suffer social and physical issues within their post-operative life but overall majority of the patients in this study reported having a good quality of life.

Pakistani culture is quite conservative and questions regarding sex and specifically personal sexual life are not easily taken by the general population, and, patients might either shy away or even confront the interviewer regarding such a question. However it is to be noted that all the patients responded well to this question and no such issues occurred. This would be one of the many few studies done in Pakistan regarding quality of life among stoma patients taking into account the sexual history as well.This study showed that the stoma patients perception towards their sexual life was equal, meaning that, approximately half of the stoma patients answered that they do not think that the stoma has caused an effect on their sexual activity and the other half say that the stoma bag has effected there sexual attractiveness and their sexual performance. A study done in the United Kingdom concluded that, as the duration for stoma patients increased post-operatively they started feeling much better and their sexual activity improved, this could be due to counseling provided to such patients as well [19]. However, in contrast to this *Carlsson et al* and *Marquis et al* studies done on the quality of life in stoma patients showed that the most of the patients had difficulty to regain their sexual activity as compared to before the surgery of the stoma bag [1] [20].A study showed that, approximately 70% of the patients were sexually active before surgery and post-operatively only 55% patients were comfortable with sex which shows approximately the same figure as our study in stoma patients[21]. Looking at the figures and comparing these studies we could conclude that there might not be any significant effectof the stoma bag with the sexual performance and attractiveness of the patient, as research does indicate a mix response in this regard. However, multiple studies in different populations need be conducted with larger sample sizes and control groups for counseling pre-operatively and post-operatively towards the sexual activity which could narrow down a more significant conclusion.

None of the independent variables showed any significant association with the quality of life among stoma patients except for the 'duration of stoma' variable. It showed that patients who had a stoma bag in place for more than six months had a better quality of life as compared to patients who had a stoma bag for less than six months. This could be most probably due to the fact that as time passed, the patients started to adopt to the changes that were required due to their stoma bag and adjusted those changes within their lifestyle. If patients have the will to accommodate and improve their social and physical quality of life, they need to encourage themselves rather than depending on others;.The mainstay of good quality oflife of a stoma patient would highly depend on the management of the stoma bag regarding its emptying and changing. If one is able to handlethe stoma bag he/shewill be able to adjust his/her lifestyle towards a better quality of life. An Iranian study supported this significant result of this study as well which observed that stoma patients took a minimum of 6 months to feel comfortable with the stoma bag [18]. Another study also showed that the physical activity within the stoma patients improved after 6 months especially in the young age people. It did also show that older people did improve till a certain period but then became static [17].

The different physical and social determinants used to seek an outcome towards the quality of life within stoma patients in this study overall showed that stoma patients in Pakistan relatively have a acceptable quality of life but*Mumtaz et al* study contradictedthis outcome, and stated that within the Pakistani population the patients did not report any perfection in their quality of life [22]. Comparison of the outcomes of our study with other studies has indicated that there is not a definite conclusion towards quality of life within stoma patients. However it is valid that physical and social factors do effect the quality of life of stoma patients and the duration of stoma does have a significant effect towards the quality of life of such patients, but still there is a great need of more intensive research in this area so that strategies of coping could be implemented for stoma patients towards a better quality of life.

STRENGHTS/LIMITATIONS

This study was focused towards a very limited population of Pakistan and included patients of mostly low socioeconomic status presenting at Civil Hospital Karachi, which are the limitations faced in this study. The strengths of the study included the response rate of the patients especially towards the question regarding their sexual activity. This study also being a cross sectional study limited the ability to build a casual association as well.

CONCLUSION

We conclude that majority of the stoma patients were able to lead a good quality of life. It also showed that there is a positive association with the duration of the stoma to the quality of life. This has shown to be supported by other studies , but this area of study needs more depth in research with a larger sample size to see what factors help the patients to lead a better quality of life as the duration of the stoma gets prolonged. More work is required with a more detailed questionnaire or qualitative study within Pakistan to come to a conclusion regarding the association of stoma patients and their physical and social quality of life, simultaneously intervening the patients with counseling and support to see whether a positive association is seen in patients. In the end it could be stated that to follow the WHO definition of health and have it implemented within the stoma patients, exclusive research and strategies based on those results need be applied for a better quality of life.

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