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QUALITY OF LIFE IN EGYPTIAN STOMA PATIENTS

By
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PURPOSE: *Although it is widely believed that patients with permanent stoma generally have a worst quality of life compared to those without, little is known about the psychological and social influence of stoma on Egyptian patients. The effects of stoma on the religious rituals could pose problems and affect the social functioning in addition to self-image. The aim of this study was to document the long-term impact of permanent stoma on the quality of life of Egyptian patients with special emphasis on the religious aspects.*

METHODS: *Over the period of data collection (three weeks) 35 patients were admitted to the study of them 7 patients were not eligible. There were 28 eligible patients (median age 55 years, min-max: 17-75 years) of them 10 were females (median age 58 years, min-max: 17-75 years) and 18 males (median age 54 years, min-max: 22-71years). A modified FIQL questionnaire was constructed to survey all possible areas of changes in quality of life after creation of stoma. The questionnaire included 39 questions were grouped under 5 types of questions according to the way of response. In addition to 3 direct questions about age, gender and the level of education. The questions were re-grouped into 5 scales: Life-style, Coping/Behavior, Depression/ Self perception, Embarrassment and Religious. Scale range from 1-5, with 1 indicating a lowest and 4 indicating a best functional status of QOL. Scale scores are the average (mean) response to all items in the scale. Not Apply (value 5) is coded as a missing value in analysis of questions.*

RESULTS: *The mean score indicated lower functional status of QOL in each of the five scales. Analysis of variance using one-way ANOVA test revealed no significant difference in between the five scales (F=1.81, p = 0.13). There was strong correlation in-between the five scales. There was no correlation between changes in scales of QOL and the level of education, gender or age. Because of stoma, 61.5% of male patients lost their jobs or became unable to work. Muslim ostomate has significant problems in preparation and during the time of prayers; 58.33% of patients have had to repeat ablution several times for each prayer interval; another 37.5% have had to empty their pouches several times before ablution; and 61% of patients were not able to pray in the mosque because of their stoma. During praying, 34.78% of patients leak stool without even knowing that. Fasting Ramadan does not disturb the stoma care of 83% of patients while 17% patients suffer from changes in bowel habits that disturb their stoma care. A significant number of Muslim ostomates (54%) cannot do Hajj because stoma interferes with their ability to travel.*

CONCLUSION: *Creation of stoma substantially diminishes the quality of life of Egyptian patients. There is a clear relation between the impact of stoma on the religious rituals and quality of life.*

Adding the religious aspects to the pre-operative counseling and to the informed consent of surgery can provide information that are necessary to make the patient's expectation more realistic and to put him in a better position to cope with the physical and psychological consequences of stoma.

Key words: *Quality of life; Stoma; Colostomy*

INTRODUCTION

Patients with stomas face many problems, both physical and psychological. Leakage caused by failure of adhesive or bag welds, ballooning of bags, poor siting, and difficulty in keeping bags in place are some of the daily problems. Anxiety and embarrassment over a stoma may lead to an alteration in life-style, including the ability to work, desire to travel, and overall self-image. The way patients feel about the changes in their bodies can affect their behavior toward family and friends; problems with sex life also occur. Some patients have initial problems with diet and clothing. The inconvenience and distress caused by this need to adapt and by other changes in lifestyle and body image have not been documented in Egyptian stoma patients [1].

Since the majority of Egyptians is Muslims, we hypothesized that the impact of stoma on the religious rituals could pose problems and affect the social functioning in addition to self-image. The Islamic faith has very definitive rules that must be followed in preparation and during the time of prayers. According to Al-Azhar Fatwa 1987 (Appendix II, III), patient in such a situation is considered to have a religiously legitimate excuse and should perform a new ablution for the new prayer interval and so on for each of the five prayer intervals. Nevertheless, information on the religious life of Muslim ostomates is lacking.

The aim of this study was to document the long-term impact of permanent stoma on the quality of life of Egyptian patients with special emphasis on the religious aspects.

PATIENTS AND METHODS

The study protocol was registered and approved by the Committee of Postgraduate Studies and Medical Research, Faculty of Medicine, University of Alexandria. The patients were identified and recruited from El Farana Clinic, Medical Insurance, Alexandria where stoma appliances are regularly provided. Inclusion criteria were: permanent stoma of more than one year with no evidence of recurrence of cancer. A modified Fecal Incontinence Quality of Life (FIQL) questionnaire (2) was constructed to survey all possible areas of changes in quality of life after creation of stoma. The questionnaire included 39 questions were grouped under 5 types of questions according to the way of response (Appendix I). In addition to 3 direct questions about age, gender and the level of education. The questions were re-grouped into 5 scales:

1-Life-style, 11 items: Q2a-f, Q2h, Q2i, Q3a, Q3c, and Q3o.

2-Coping/Behavior, 11 items: Q2g, Q2j, Q2k, Q2l, Q2n, Q3d, Q3j, Q3l, Q3n, Q3p, Q3q.

3-Depression/ Self perception 7 items: Q1 (reverse coded), Q3e, Q3h, Q3i, Q3k, Q3m, Q4.

4-Embarrassment, 4 items: Q2m, Q3b, Q3f, Q3i

5-Religious 6 items: Q5 a-f

Scale range from 1-5, with 1 indicating a lowest and 4 indicating a best functional status of QOL. Scale scores are the average (mean) response to all items in the scale. Not Apply (value 5) is coded as a missing value in analysis of questions.

Statistical analyses: all data were entered in a computer database and analyzed by using SPSS software. To test for difference between subgroups the *t*-test and one-way ANOVA were used for quantitative variables. The correlation between scales was analyzed using Spearman correlation coefficient. Difference was considered significant at $p < 0.05$

RESULTS

Over the period of data collection (three weeks) 35 patients were admitted to the study of them 7 patients were not eligible. Reasons for exclusion were potential mode effects during interview (4 patients), too old or too ill to approach (2 patients) and one patient with evidences of tumor recurrence. Data were collected from self-administered survey in 10 patients and through interview in the remaining 18 patients. There were 28 eligible patients (median age 55 years, min-max: 17-75 years) of them 10 were females (median age 58 years, min-max: 17-75 years) and 18 males (median age 54 years, min-max: 22-71years).

Before creation of stoma, 5 male patients were retired and 13 patients were working of them 8 patients (61.5%) lost their jobs or became unable to work because of stoma. All female patients were not working before creation of stoma.

The majority of the patients (18 patients, 64.28%) did not graduate from secondary school, 6 patients (21.43%) were secondary school graduates and 4 patients (14.29%) have completed 4 years college degree. There was no correlation between changes in scales of QOL and the level of education (Table 1)

Questions related to sex life were either not applicable or unanswered in 10 (35.71%) of patients. Of those who answered, 7 (38.88%) patients had significant problems with their sex lives.

Question related to ablution before praying was answered by 24 patients (85.7%), of them 14 patients (58.33%) have to repeat ablution several times for each prayer interval. Another 9 patients (37.5%) have to empty their pouches several times before ablution. This means that those patients were not informed about the Al-Azhar Fatwa about religiously legitimate excuse offered in such

situation. Question related to praying in the mosque was answered by 23 patients, of them 14 (61%) patients were not able to pray in the mosque because of their stoma. During praying, 8 (34.78%) patients leak stool without even knowing that.

Fasting Ramadan does not disturb the stoma care of 20 (83%) patients while 4 (17%) patients suffer from changes in bowel habits that disturb their stoma care. Twenty-four patients were concerned about doing the Hajj worship, of them 13 (54%) could not do it because of their stoma interfere with their ability to travel.

When the scores of the five scales of QOL were compared in relation to gender, there was no significant difference, although, the scores of male patients were slightly better than those of female patients (Table 2). Moreover, there was no correlation between changes in QOL and gender (Table 1).

To examine the effect of age on the QOL in stoma patients, the patients were divided into two groups. There was no significant difference in scale scores of patients aged 55 years old or older if compared to younger group (Table 3) and no correlation between changes in different scales and age (Table 1).

The mean score indicated lower functional status of QOL in each of the five scales. Analysis of variance using one-way ANOVA test revealed no significant difference in between the five scales (F=1.81, p = 0.13). There was strong correlation in-between the five scales (Table 1). Although there was a weak correlation between the type of religion and life-style, coping/behavior and religious aspects scales, this should be considered incorrect because of the small number of Christian patients (2 patients) included in this study.

Table 1*: Correlations in between the five scales of quality of life and with age, gender education and type of religion*

Scale	*2.Coping/Behavior*	*3.Depression/Self Perception*	*4.Embarrassment*	*5.Religious Aspects*	*Gender*	*Age*	*Education*	*Religion*
1.Life Style	0.876**	0.661**	0.748**	0.652**	0.331	-0.232	0.019	0.389*
2. Coping/Behavior		0.746**	0.797**	0.714**	0.153	-0.253	0.037	0.443*
3. Depression/Self Perception			0.732**	0.684**	0.334	-0.045	-0.173	0.160
4. Embarrassment				0.615**	0.288	-0.217	-0.151	0.228
5. Religious Aspects					0.026	-0.260	0.013	0.464*

*** Correlation is significant at the 0.01 level (2-tailed).***

** Correlation is significant at the 0.05 level (2-tailed).***

Table 2: *Quality of life scale scores (Total, females and males)*

Scale	*Total Score (n=28)*	*Females (n=10*	*Males (n=18)*	*p*
Scale 1. Life Style	2.06/0.94	1.65/0.85	2.29/0.94	0.09
Scale 2. Coping/Behavior	1.86/0.84	1.69/0.76	1.95/0.88	0.44
Scale 3. Depression/Self Perception	2.35/0.89	1.96/0.94	2.57/0.80	0.08
Scale 4. Embarrassment	1.79/0.88	1.45/0.91	1.97/0.84	0.14
Scale 5. Religious Aspects	2.00/0.78	1.97/0.76	2.01/0.81	0.90

Figures are mean/ standard deviation

Table 3: *Quality of life scale scores (Patients <55 years vs. Patients ≥ 55 years)*

Scale	*Patients <55 years (n=13)*	*Patients ≥ 55years (n=15)*	*p*
Scale 1. Life Style	2.21/0.98	1.94 /0.93	0.46
Scale 2. Coping/Behavior	2.06/0.90	1.68/0.76	0.24
Scale 3. Depression/Self Perception	2.38/1.09	2.33/0.71	0.89
Scale 4. Embarrassment	1.87/0.93	1.72/0.87	0.67
Scale 5. Religious Aspects	***2.18/0.84***	***1.82/0.70***	***0.24***

Figures are mean/ standard deviation

DISCUSSION

This study confirmed the suspicion that Egyptian patients have a long-term difficulty in adjusting to life with stoma. The Modified Fecal Incontinence Quality of Life (FIQL) questionnaire revealed that creation of stoma substantially diminishes all areas (scales) of the quality of life in Egyptian patients. The functional scores of QOL were equally diminished in each of the five scales ($F=1.81$, $p = 0.13$) with strong correlation in-between the five scales.

The FIQL [2] as originally designed to measure the quality of life of patients with fecal incontinence, has met the psychometric criteria for reliability and validity. Prior efforts to measure the quality of life of stoma patients relied on clinicians' opinions of salient elements [1,3]. Some authors used the Nottingham Health Profile or Questionnaire for Attitudes Toward Quality of Health and Quality of Life to assess the life style issues of stoma patients [4], but to our knowledge there is no validated QOL instrument for stomas.

Worldwide reports concerning the psychosocial impact of stomas on a patient's quality of life are scarce. As early as 1947, Dukes [5] reported a series of 100 patients in whom he identified a high level of reactive depression after the construction of a colostomy. This and repeated similar observations were confirmed by modern quality-of-life research instruments by authors such as Williams and Johnston [6]. In their study patients with stomas had high scores on depression (35%) and reported a change in their body image (66%). In recent quality-of-life study by Sprangers and coworkers [7] reported that impairments are limited to some domains of quality of life (physical, psychosocial and sexual).

In the current study, it was shown that the impact of stoma on the quality of life is more prominent in Egyptian patients in the view of the worldwide reports. Moreover, impairment involved all domains of quality of life in our patients that is not coincides with the observations in the western community.

After creation of stoma, 38.5% of our male patients were able to return to their jobs. We could not estimate the overall impact of stoma on the ability to work because all female patients, included in this study, were not working before creation of stoma. However, the frequency of men losing jobs or being unable to work in our study (61.5%) is higher than that reported in literature. Sprangers and coworkers [7] reported that 40% of stoma patients returned to their jobs. In the study of Nugent et al [1], only 8% of stoma patients had changed their work while most of the stoma patients had no effect on their work or ability to find work.

In the current study, questions related to sex life were either not applicable or unanswered in 35.71% of patients. Of those who answered, 38.88% of patients had significant problems with their sex lives. These results correlate well with those found in the literature. Nugent et al [1] reported that questions related to sex life were either not applicable or unanswered in 51% of colostomy patients. In the largest study of 16.470 American stoma patients [8], 59% of colostomy patients had problems with their sex lives. Many patients reported significant problems that seemed to be related to pelvic surgery (impotence and dyspareunia) rather than the creation of the stoma itself. An in-depth study by Awad et al [9] found that 32 % of stoma patient considered sex is physically difficult and 46% of them found sex psychologically difficult.

We found a surprising wide range of responses to questions relating to quality of life, with some patients coping extremely well with their stomas, and others finding them both distressing and disruptive to their lifestyles. This may be related to age, gender or the level of patient's education. Older patients may not adapt well to stoma; however, there was no significant difference in scale scores of patients aged 55 years old or older if compared to younger group and no correlation between changes in different scales and age. This correlates well with the observation of Stryker et al [10] that older fared as well or better than the younger group. Moreover, there was no significant difference between the scores of male patients and those of female patients. We were surprised by the absence of correlation between changes in scales of QOL and the level of patient's education.

In the current study, it was evident that Muslim ostomate has a significant problems in preparation and during the time of prayers. Most of these problems are due to unawareness of the patients about the Al-Azhar Fatwa about the religiously legitimate excuse offered in such situation. This is a result of deficient preoperative counseling and the very low intake of stoma support groups and other patient associations in Egypt.

In Islamic faith praying in the mosque has the advantage over praying alone in the house. The majority (61%) of Muslim ostomates do not pray in the mosque for fear of smell. Accordingly some of them feel guilty if they had been used to pray in the mosque before creation of stoma. Moreover, a significant number of Muslim ostomates (54%) cannot do Hajj because stoma interferes with their ability to travel.

This study confirms that having a stoma has a great impact on the patient's religious life. The clear relation between the impact of stoma on religious life and the other domains of quality of life has not been described before. The conclusion is that adding the religious aspects to the pre-operative counseling and to the informed consent of surgery is necessary to make the patient's expectation more realistic and to put him in a better position to cope with the

consequences of stoma. In Egypt, stoma care nursing (stoma therapists) is substantially deficient and if improved might contribute to an improvement in the quality of life of these patients.

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Appendix 1: Modified Fecal Incontinence Quality of Life Instrument for Stoma Patients

Q.1 In general, would you say your health is:

	For office
☐ Excellent	1
☐ Very Good	2
☐ Good	3
☐ Fair	4
☐ Poor	5

Q.2: For each of the items, please indicate how much of the time the issue is a concern to you due to your stoma. (If it is a concern for you for reasons other than your colostomy then check the box under Not Apply, (N/A).

Due to my colostomy:	Most of the time	Some of the Time	A Little of the Time	None of the Time	N/A
a. I am afraid to go out	☐	☐	☐	☐	☐
b. I avoid prolonged physical activity	☐	☐	☐	☐	☐
c. I avoid visiting friends	☐	☐	☐	☐	☐
d. I avoid staying overnight away from home	☐	☐	☐	☐	☐
e. It is difficult for me to get out and do things like going to a movie or to church	☐	☐	☐	☐	☐
f. I cut down on how much I eat before I go out	☐	☐	☐	☐	☐
g. Whenever I am away from home, I try to stay near a restroom as much as possible	☐	☐	☐	☐	☐
h. It is important to plan my schedule (daily activities) around my bowel pattern	☐	☐	☐	☐	☐
i. I avoid traveling	☐	☐	☐	☐	☐
j. I worry about not being able to take care of my colostomy	☐	☐	☐	☐	☐
k. I feel I Have no control over my stoma	☐	☐	☐	☐	☐
l. I can't empty my stoma bag in time	☐	☐	☐	☐	☐
m. I leak stool without even Knowing it	☐	☐	☐	☐	☐
n. I try to prevent stoma accidents by staying very near a bathroom	☐	☐	☐	☐	☐
For office use only	1	2	3	4	5

Q.3: Due to your stoma, indicate the extent to which you *Agree or Disagree* with each of the following items. (If it is a concern for you for reasons other than your colostomy then check the box under Not Apply, N/A).

Due to my colostomy:	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	N/A
a. I no longer eat some of the foods I like	☐	☐	☐	☐	☐
b. I feel ashamed	☐	☐	☐	☐	☐
c. I can not do many things I want to do	☐	☐	☐	☐	☐
d. I worry about stoma problems	☐	☐	☐	☐	☐
e. I feel depressed	☐	☐	☐	☐	☐
f. I worry about others smelling stool on me	☐	☐	☐	☐	☐
g. I worry about being embarrassed or humiliated	☐	☐	☐	☐	☐
h. I feel like I am not a healthy person	☐	☐	☐	☐	☐
i. I enjoy life less	☐	☐	☐	☐	☐
j. I have sex less often than I would like to	☐	☐	☐	☐	☐
k. I feel different from other people	☐	☐	☐	☐	☐
l. The possibility of stoma problems is always on my mind	☐	☐	☐	☐	☐
m. I am afraid to have sex	☐	☐	☐	☐	☐
n. I avoid traveling by plane or train	☐	☐	☐	☐	☐
o. I avoid going out to eat	☐	☐	☐	☐	☐
p. Whenever I go someplace new, I specifically locate where the bathrooms are	☐	☐	☐	☐	☐
q. My life is more difficult	☐	☐	☐	☐	☐
For office use only	1	2	3	4	5

Q.4: During the past month, have you felt so sad, discouraged, hopeless, or had so many problems that you wondered if anything was worthwhile?

1	☐	Extremely So –To the point that I have just about given up
2	☐	Very much so
3	☐	Quite a Bit
4	☐	Some -Enough to bother me
5	☐	A little Bit
6	☐	Not at All
For office		

Q.5: For each of the items, please indicate how much of the time the issue is a concern to you due to your stoma. (If it is a concern for you for reasons other than your colostomy then check the box under Not Apply, (N/A).

Due to my colostomy:	Most of the time	Some of the Time	A Little of the Time	None of the Time	N/A
a. I have to repeat ablution before praying	☐	☐	☐	☐	☐
b. I have to empty my stoma bag several times before ablution	☐	☐	☐	☐	☐
c. During praying, I leak stool without even Knowing it	☐	☐	☐	☐	☐
d. It is difficult for me to go to mosque or to church	☐	☐	☐	☐	☐
e. Fasting Ramadan disturbs my stoma care	☐	☐	☐	☐	☐
f. Because I avoid traveling, it is difficult for me to do Hajj or Omra	☐	☐	☐	☐	☐
For office use only	1	2	3	4	5

Finally, we would like to ask you some basic demographic questions that will help us in the analysis of these results:

Q.6:

Are you	☐	Female	1
	☐	Male	2

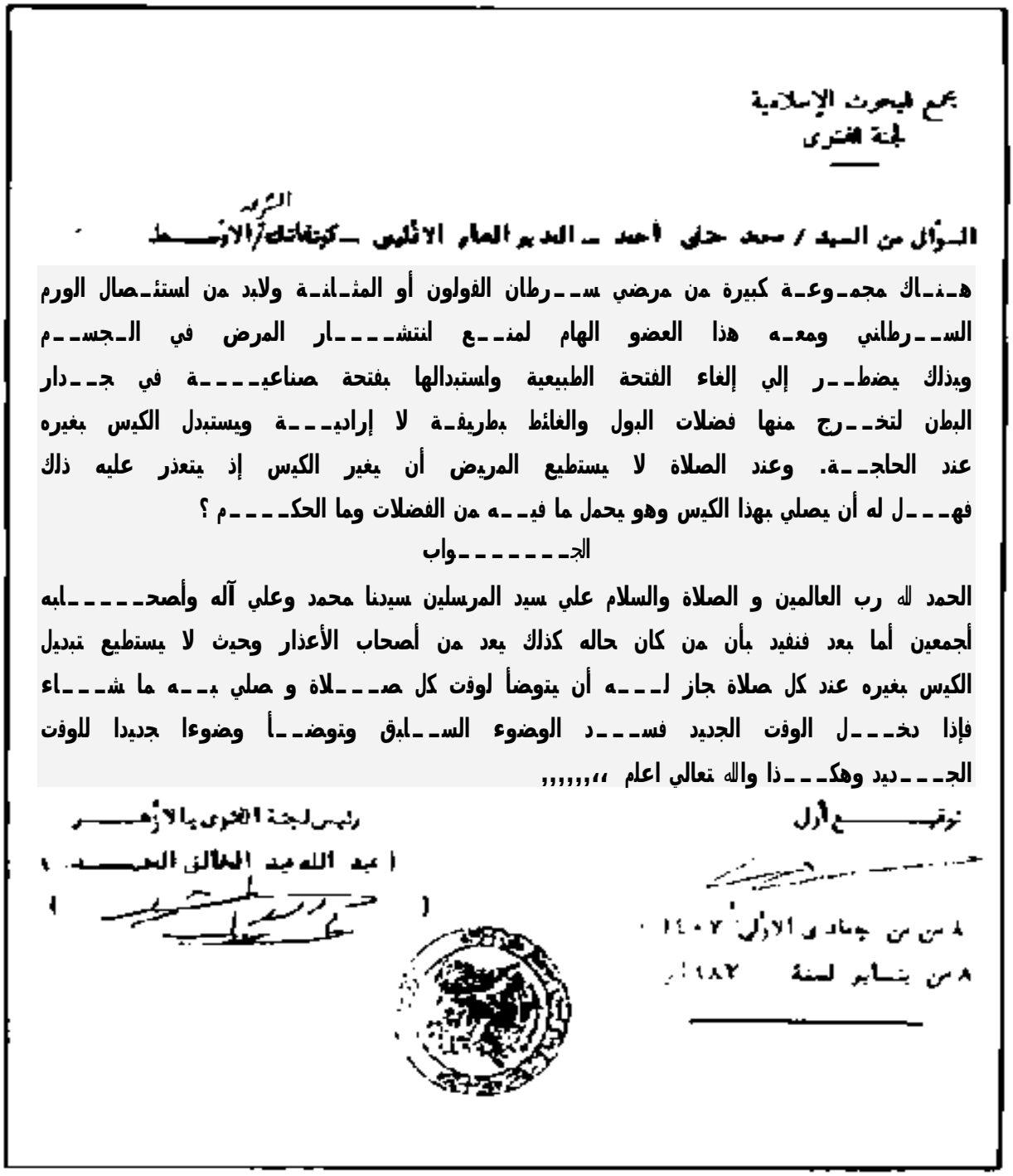
Q.7: How old are you?
_____ Years

Q.8: Please indicate the highest level of education you have completed:

For office

1 ☐ Did not graduate from School
2 ☐ Secondary School Graduate
3 ☐ Some College or Technical School
4 ☐ 2 Year College or Vocational –Technical Degree
5 ☐ 4 Year College Degree
6 ☐ Post-Graduate Degree

Appendix I1: Fatwa about preparation for prayer for Muslim Ostomates (In Arabic)



مجمع البحوث الإسلامية
لجنة الفتوى

السؤال من السيد / محمد حلمي أحمد ـ الدير العام الأقليمي ـ كويتفاتك/الأوسط

هناك مجموعة كبيرة من مرضي سرطان القولون أو المثانة ولابد من استئصال الورم السرطاني ومعه هذا العضو الهام لمنع انتشار المرض في الجسم وبذلك يضطر إلي إلغاء الفتحة الطبيعية واستبدالها بفتحة صناعية في جدار البطن لتخرج منها فضلات البول والغائط بطريقة لا إرادية ويستبدل الكيس بغيره عند الحاجة. وعند الصلاة لا يستطيع المريض أن يغير الكيس إذ يتعذر عليه ذلك فهل له أن يصلي بهذا الكيس وهو يحمل ما فيه من الفضلات وما الحكم ؟

الجواب

الحمد لله رب العالمين و الصلاة والسلام علي سيد المرسلين سيدنا محمد وعلي آله وأصحابه أجمعين أما بعد فنفيد بأن من كان حاله كذلك يعد من أصحاب الأعذار وحيث لا يستطيع تبديل الكيس بغيره عند كل صلاة جاز له أن يتوضأ لوقت كل صلاة و صلي به ما شاء فإذا دخل الوقت الجديد فسد الوضوء السابق وتوضأ وضوءا جديدا للوقت الجديد وهكذا والله تعالي اعلم ,,,,,,,

توقيع أول

٨ من جمادى الأولى ١٤٠٢ هـ
٨ من يناير لسنة ١٩٨٢ م

رئيس لجنة الفتوى بالأزهر
عبد اللطيف عبد الخالق السيد

From: The web site of The International Ostomy Association
http://www.ostomyinternational.org

Appendix II1: Fatwa about preparation for prayer for Muslim Ostomates (In English)

In the name of Allah, the most Gracious, the most Merciful.
AL-AZHAR Complex of Islamic Research
Fatwa Commission
(Counselling Islamic Commission)

Question

Submitted by Mr. Mohamed Hanafy Ahmed, General Manager of ConvaTec, Middle East: "There is a large group of patients afflicted by colon and bladder cancer where the malignant tumor has to be removed together with the vital organ of the body so as to prevent the spread of disease. In such cases the natural opening of the body is by-passed and replaced by a stoma in the abdomen to work as an outlet through which urine or stool is emitted in an involuntary manner. Pouches used for collecting such matter are replaced when necessary.At the time of prayers, the stoma patient is unable to change the pouch. Is it possible for such a patient to pray while the pouch is carrying such excrements and what is the rule in such a case ?"

Answer

Praised be Allah, Lord of all creatures and peace and prayers be upon the master of messengers Mohamed, his Kin and his followers.

"In answer to this question, we reply that whoever is in such a situation is considered to have a religiously legitimate excuse. Since a stoma patient cannot replace the pouch for each prayer, he may perform ablution at the onset of each prayer interval. He may then pray as many times as he may wish during this prayer interval. At the onset of a new prayer interval, the ablution performed in the last interval is no longer valid and the stoma patient should perform a new ablution for the new prayer interval and so on (for each of the five prayer intervals.)

"Allah, Glory to be him is more knowledgeable than all."

First Signature

Chairman of Fatwa Commission of AL-AZHAR
Abd Allah Abd-Alkalik Al Mishad
8 Jumada 1, 1407
8 January 1987

From: The web site of The International Ostomy Association
http://www.ostomyinternational.org