

## Knowledge, Self-care Practices and Quality of life among Patients With Urostomy

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### Abstract

**Background:** Urostomy is a surgical procedure that redirects the flow of urine following a cystectomy. Patient's knowledge regarding disease and self-care practices are important to achieve the desired treatment targets and improve quality of life. **Aim of the study:** To assess knowledge, self-care practices and quality of life among patients with urostomy. **Research design:** A descriptive design was used. **Setting:** The study was conducted at urology surgery department and urology outpatient clinic in Fayoum University Hospital. **Methods:** A purposive sample of 60 adult patients from both genders with urostomy. **Tools:** four tools were utilized for data collection **Tool (I):** Structured interview questionnaire, **Tool (II):** patient's knowledge assessment questionnaire, **Tool (III):** patients practice observational checklist **and Tool (IV):** Quality of Life Assessment Questionnaire. **Results:** The results of this study revealed that 96.7% of patients had an unsatisfactory level of knowledge and self-care practices related to urostomy care and 70% of patients had sever disability of quality of life. **Conclusion:** It can conclude that, the highest percentage of patients had unsatisfactory knowledge, unsatisfactory self-care practices and poor quality of life related to urostomy care. **Recommendations:** Design and apply nursing program to improve knowledge, self-care practices and quality of life among urostomy patient.

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**Keywords:** Knowledge, Self-care, quality of life, urostomy

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### Introduction

The Bladder cancer is the most common malignant tumor of the urinary system with high morbidity rate and no clear pathogenesis (*Huang, et al., 2025*). Radical cystectomy with urinary diversion (RCUD) remains the standard of care for the treatment of very high-risk non—muscle-invasive or muscle-invasive bladder cancer. A urostomy is the most common type of urinary diversion, also called a noncontinent UD, requires an external pouch—a disposable plastic bag that sticks to the skin of the abdomen (*Veccia, et al., 2024*).

Patient knowledge regarding disease and self-care practices are found to be important for patients to achieve the desired treatment targets and contribute meaningfully in the management of their disease (*Niguse, et al., 2019*). In health care, self-care means that patients and families should be allowed to make decisions and take initiative, responsibility and participate in matters regarding their own health.

Regarding to quality of life, *Wolanin (2021)* demonstrated that, quality of life is described as the extent to which an individual can achieve security, self-esteem, and opportunities to utilize their intellectual and physical capabilities in pursuit of personal goals, resulting in satisfaction in areas such as physical, psychological, social, mental, and spiritual needs. *Bozkul et al., (2024)* recommends that, Urostomy immensely effect on the patient's everyday life from minor physical activity to social relations. Various factors, such as loss of control over the urine elimination, pouch leaks, bad odor, flatulence, not only can

negatively influence the self-esteem and confidence of the of the patients but also compromise the social well-being.

Nurses are a perfect reference point for both patients and families when it comes to ensure knowledge of self-care and adaptation to the new situation with the highest possible quality of life. Hence, health professionals must dynamically and carefully intervene in improving patients' self-care ability through well-designed and effective caring systems (*Riegel et al., 2021*).

### Significance of the study:

Urostomy is a life-saving surgical procedure, yet it significantly alters patients' daily life, body image, and self-care demands. Assessing patients' knowledge and self-care practices is crucial because inadequate understanding and poor management of the stoma may lead to serious complications such as infections, leakage, and peristomal skin problems. Moreover, the level of patients' knowledge and their ability to perform proper self-care directly affect their quality of life, including physical, psychological, and social well-being. Therefore, this study is significant as it provides insights into the gaps in knowledge and self-care practices among patients with urostomy, highlights the challenges they face in adapting to their new lifestyle, and guides healthcare professionals in developing targeted educational programs (*Marcomini et al. 2024*).

### Aim of the study

The study aimed to assess knowledge, self-care practices and quality of life among patients with urostomy, through:

1. Assess patient's knowledge regarding urostomy.
2. Assess patient's self-care practices regarding urostomy.
3. Assess patient's quality of life regarding urostomy

### Research question:

1. What are the levels of knowledge among patients with urostomy?
2. What are the levels of self-care practices among patients with urostomy?
3. What are the levels of quality of life among patients with urostomy?

### Subject and Method

#### Research Design:

A descriptive Correlational study design was utilized to conduct the study. It's a non-experimental quantitative research design used to: Describe the current status of variables in a population and examine the relationships (correlations) between two or more variables without manipulating them. (*Olawale et al., 2023; Devi et al., 2022*).

#### Setting:

This study was conducted at Urology Outpatient Clinic and Urology Surgery department in Fayoum University Hospital. The Urology Outpatient Clinic consists of 2 sections; the first section consists of physician office, the second section is an examination room. The Urology Surgery department consists of 3 sections; the first sections for male and it includes 16 beds , the second section for female and it includes 9 beds, the third section for nurses. The nursing section includes an office, medication section and needed equipment.

#### Subject:

Based on Purposive sample of 60 adult patients from both genders sample size equation (*Steven, 2014*), recruited from the previously mentioned setting undergoing percutaneous nephrostomy tube

participate in this study. The sample size was calculated by adjusting the power of the test to 80% and the confidence interval to 95% with margin of error accepted, adjusted to 5%.

- P= 0.5
- N= Total population = 100
- Z= Z value “1.96”
- D= Standard Error
- n= sample size

$$n = \frac{N \times p(1-p)}{\left[ \left[ N-1 \times \left( d^2 \div z^2 \right) \right] + p(1-p) \right]}$$

#### Inclusion criteria:

- Adult Patients from both genders agree to participate in the study, Patients with urostomy after radical cystectomy and Patient fully conscious and able to communicate verbally.

#### Exclusion criteria:

- Patients with physical or psychological disabilities.

#### Tools of Data Collection:

Four tools were used to collect the data according to the following :

##### Tool I: Interview Patient’s assessment Questionnaire:

It developed by the researcher in English and Arabic language based on relevant, recent literatures (*Smeltzer, et al., 2018*) to collect baseline data pertinent to the current study. It was consisted of two parts as follow:

**Part (1):** patient Socio-demographic data: This part concerned with patients' age, gender, marital status, educational level, occupation and residence.

**Part (2):** Patients' related medical past and current history: it includes information about know what disease you are suffering from, data related to previous hospitalization, sign and symptoms, chronic diseases, family history.

##### Tool II: patient's knowledge assessment questionnaire.

This tool developed by the researcher after reviewing related *literatures* (*Stromberg, 2021 ; Berti-Hearn & Elliott, 2019* ) to assess patients knowledge regarding urostomy patients after radical cystectomy and including the following parts:

**Part I:** this part contains questions anatomy of urinary system, bladder cancer, definition of radical cystectomy, and general knowledge about definition of urostomy and type of urostomy.

**Part II:** Patients' knowledge about urostomy.

**Part III:** knowledge about activity of daily living.

**Scoring system:** Patient's knowledge assessment questionnaire consisted of 28 questions, the correct answers were predetermined according to literature review, a correct answer was scored 1 point and incorrect answer was scored 0 point, and satisfactory level was detected was detected based on *Badour(2023)*, statistical analysis as following:

- Satisfactory knowledge level  $\geq 70\%$
- Unsatisfactory knowledge level  $< 70\%$

##### Tool (III): patient's Urostomy Self-Care reported Practice Checklist:

This tool developed by the researchers based on the related literature (*Berman, et al., 2016& Perry, et al., 2021*). To assess self-care practices. It was consisted of 3 main parts as the following:

**Part I:** to assess patient's practice regarding change pouch.

**Part II:** to assess patient's practice regarding Skin care around urostomy bag.

**Part III:** to assess patient's practice regarding empty pouch.

**Scoring system:** the total items of checklist were (23); each step has 2 levels of answers (not done, done completely). The score of the items were summed up and the total divided by the number of items, giving a mean score. And satisfactory level of practice was detected based on *Badour(2023)*, statistical analysis as following:

- Satisfactory practice level  $\geq 70\% = \geq 16$  degree.
- Unsatisfactory practice level  $< 70\% = < 16$  degree.

#### **Tool (V): Quality of Life Assessment Questionnaire:**

Patients with urostomy will be assessed by City of Hope Quality of Life-Ostomy Questionnaire (CoH-QoL-OQ) for their quality of life. This tool will be adapted from (*Grant et al.,2004*) and translated into Arabic by researchers. It contains questions related to 4 domains of life i.e Physical (1-11 items), Psychological (12-24 items), Social (25- 36 items) and Spiritual (37-43 items).

#### **Scoring system for Quality of Life Assessment Questionnaire:**

Patient Quality of Life-Ostomy assessment Questionnaire consisted of 43 questions, Subjects were asked to respond to each item with a score of 1-10. A high score indicate good quality of life and low score indicate poor quality of life. The level of Quality of life was categorized as per the scores into Very severe (0-25%), Severe (26-50%), Moderate (51-75%) and Mild ( $>75\%$ ). **This scoring system supported by *Sraw et al (2017)*.**

#### **Validity:**

The content validity of the tools was done by a panel of 7 experts in nursing and medicine, who reviewed the content of the tools for comprehensiveness, accuracy, clarity, relevance and applicability. Suggestions were given and modifications were done.

#### **Reliability:**

Reliability of the tool was tested to determine the extent to which the questionnaire items are related to each other. The Cronbach's alpha model, which is a model of internal consistency, was used in the analysis. Statistical equation of Cronbach's alpha reliability coefficient normally ranges between 0 and 1. Higher values of Cronbach's alpha (more than 0.7) denote acceptable reliability

#### **Ethical consideration:**

An official permission was obtained from the administrative authority of the selected setting for the current study. The researcher obtained consent from the studied patients, explaining the purpose and nature of the study, stating the possibility to withdraw at any time. Confidentiality of data assured by using codes to identify participants.

#### **Pilot study:**

A Pilot study was carried out with 10% (10 patients) of the sample under study to test the applicability, clarity and efficiency of the tools, then the tools modified according to the results of the pilot study. Modifications included: rephrasing and rearrangement of some questions. After modification, the final form of the tools was developed. Patients who shared in pilot study excluded from the study sample.

#### **Field Work:**

- Study was conducted within six months from May 2024 to the end of October 2024.
- The researcher visited the selected setting regularly, three days per week from 9 am to 3 pm, select patient according to inclusion criteria.

- Structured interview schedule was done with every participant alone to assess his/her knowledge, self-care practices and quality of life. The interview was done during first visit outpatient clinical at the urology clinic. in a quiet and private setting to ensure comfort and confidentiality. Data collection was carried out using four validated tools. Range of cases about 1 to 3 per day from the two days of working field to gather data using the previously mentioned tools .
- The time consumed to fill in the tool by the researcher was 20 minutes for each tool.
- An oral and written informed consent was obtained from each participant prior to data collection
- Before starting in data collection; the purpose of the study was simply explained to the patients and their families who agree to participate in the study prior to any data collection.

### Statistical Design:

Data were extracted from the interview questionnaire and computerized in IBM SPSS statistic for windows, version 20.0. Armonk, NY: IBM Crop. Data analyzed was done using a software package. Data were presented using descriptive statistics in the form of frequencies and percentages for qualitative variable, and mean and standard deviations for quantitative variables. The statistical analysis was done using the mean, standard deviation, unpaired student t-test and ANOVA test. The **P-value < 0.05** considered as statistical significant.

### Results:

**Table (1):** Distribution of demographic characteristics for patients with urostomy (n= 60).

demographic data	Study group (n=60)	
	N	%
Age		
Mean±SD	63.166±7.4	
Gender		
Male	48	80
Female	12	20
Social Status		
Single	2	3.3
Married	46	76.7
Divorced	2	3.3
Widowed	10	16.7
Level of Education		
Can't read and write	38	63.3
Read and write	16	26.7

Moderate qualified	4	6.7
Highly qualified	2	3.3
<b>Occupation</b>		
Doesn't work	34	56.7
Employee	2	3.3
Retried	18	30
Housewife	6	10
<b>Place of residence</b>		
Urban	16	26.7
Rural	44	73.3

**Table (1)** illustrates that, as regarding demographic characteristics, the mean age of the studied patients was  $63.166 \pm 7.4$ . the majorities of the studied patients were males 80%, added married 76.7%, A large proportion in studied patients are either not able to read and write or have basic literacy 63.3%, majority Studied patients not working 56.7% , regards to residence 73.3% were from rural residence.

**Table (2):** Distribution of health related data for patients with urostomy (n=60).

Variable	Study group (n=60)	
	N	%
<b>Do you knowing the disease he suffered from:</b>		
No	12	20
Yes	48	80
<b>Way of discovering the disease:</b>		
By chance	0	0
As a result of your symptoms	60	100
<b>Symptoms suffering from it:</b>		
Blood in urine	2	3.3
Frequent urination	2	3.3
Burning urination	18	30

Urinary retention	1	3.3
Blood in urine& Burning urination	16	26.7
Burning urination &Pain in the lower abdomen	20	33.3
<b>Receiving treatment for bladder cancer:</b>		
No	42	70
Cystoscope	10	16.7
Radiotherapy& Cystoscope	8	13.3
<b>Suffering from other chronic diseases:</b>		
No	23	53.4
Diabetes	14	23.3
Hypertension	14	23.3
Renal impairment	0	0
<b>Family History of bladder Cancer:</b>		
No	46	76.7
Second	8	13.3
Third	6	10

**Table (2)** illustrated that there was the most common symptom in both groups is 'Burning urination & Pain in the lower abdomen' (33.3%). the majority of them did not receive treatment for bladder cancer (70%). The most common conditions are diabetes and hypertension. Most participants do not have a family history of bladder cancer (76.7%).

**Table (3):** Distribution of knowledge levels for patients with urostomy (n=60).

Variables	Studied patient (N=60)	
	No.	%
Knowledge		
Unsatisfactory level	58	96.7%
Satisfactory level	2	3.3%

**Table (3)** showed that; there was a high percentage of unsatisfactory level of knowledge 96.7% regarding urostomy among studied patients.



**Table (4):** Distribution of practice levels for patients with urostomy (n=60).

Variables	Studied patients (N=60)	
	No.	%
Self-care practice		
Unsatisfactory level	58	96.7%
Satisfactory level	2	3.3%

**Table 4:** illustrates that, 96.7% of the studied patients had unsatisfactory level of self-care practice regarding urostomy, while only 3.3% had good level of practice.

**Table (5):** Distribution of the patient's total quality of life among patients with urostomy (n=60).

Variable	Total QOL		$\chi^2$	P-Value
	N	%		
Very Sever	14	23.3	69.28	0.000*
Sever	42	70		
Moderate	4	6.7		
Mild	0	0		
Test & P-Value	$\chi^2 =$ 2.55 (0.279)			

**Table 5:** illustrates that, 70% of the studied patients had severe disability of quality of life, while only 6.7% had moderate disability of quality of life.

**Table (6):** Correlation between total knowledge score, total self-care practices and quality of life among patients with urostomy (n=60).

	Total knowledge score	
	R	P-value
Total self-care practice score	0.622	0.001**
Total QOL	0.425	0.001*

**Table (6):** illustrates that, there was a highly statistically significant positive correlation between total knowledge, total self-care practices and quality of life among patients with urostomy with p-value 0.001.



## Discussion

Bladder cancer is one of the most prevalent malignant tumors of the urinary system and one of the cancers with the highest fatality rate. Patients who do not have the resources or skills to effectively manage their condition are subject to resulting complications (*Gao et al., 2022*).

The present study findings revealed that, the mean age of the studied patients in was ( $63.166 \pm 7.4$ ) respectively. This finding is on the same line with *Hao et al., (2022)* who conducted "Effect of the whole seamless connection of nursing from WeChat interactive platform on stigma and quality of life in patients with urinary system cancer.", reported that mean age of the studied patients was ( $64.8 \pm 12.58$ ).

**Regarding patients' gender**, the current study demonstrated that, majority studied patients were male. This means that, males were more prone to be affected than females, may be due to the risk factors that cause bladder cancer like cigarette smoking which is known to increase the risk of developing transitional cell carcinoma. Also, industrial exposure to known carcinogens constitutes a significant risk factor. Men usually occupy these types of work. This result was in agreement with (*Serag et al., 2022*), who conducted a study entitled "Psycho-Educational Nursing Program for Enhancement the Quality of Life among Bladder Cancer Patients with Urinary Diversion" and found that majority of patients were male.

**Regarding patients' marital status**, the current study demonstrated that, majority of the studied patients were married. This result may be due to the disease mostly affecting older patients and majority of them were married. This result was in agreement with (*Rammant et al., 2020*) who conducted a study entitled "Health-related quality of life overview after different curative treatment options in muscle invasive bladder cancer" and found that majority of patients were married.

**Concerning educational level of the studied subjects**, the result of this study illustrated that more than half of the studied subjects were can't read or write. As it is expected this result differs from the results of many other studies that were conducted in other countries and places which mentioned that almost half of the sample have middle and high education *Pham et al., et al., (2019) and Jung et al., (2020)*. The finding could be interpreted in light of the fact that the majority the studied subjects came from rural area which doesn't consider education a top priority.

**As regards occupation** more than half of the studied patients were not working. This result may be attributed to that, about half of patients' age were more than fifty years and in a retirement age and their health condition forced them to stop working. This result is in line with *Serag et al., (2022)*. Who conducted a study entitled "Psycho-Educational Nursing Program for Enhancement the Quality of Life among Bladder Cancer Patients with Urinary Diversion" and found that half of the studied patients were unemployed.

**Regarding the place of residence**, the majority of the studied predominantly come from rural areas. This finding is similar to the finding of *Ibrahim et al., (2022)* who conducted "the effect of nursing instructions on self-efficacy and urostomal complications among patients with ileal conduit" reported that, the majority of the studied patients came from rural areas,

**Concerning medical diagnosis firstly disease discovery**, the present study emphasized that the majority of the studied patients discovered the disease through symptoms like blood in urine, burning and difficult urination, This result is in line with *Abdel-Wahid, (2022)* who conducted "Nurse Led Intervention to Enhance Self-care Efficacy among Patients Undergoing Urinary Diversion at Urology and Nephrology Center- Mansoura University" pointed out that, the all patients in both groups discovered the disease through symptoms like blood in urine, burning and difficult urination.

**In relation to chronic diseases**, this study showed that about one third of patients suffer from hypertension or DM, this is agreed with the result of *zahrn et al. (2017)* who reported that about one third

of his study sample suffer from comorbidities (DM& hypertension) and the result of *Deb et al. (2020)* who reported that frequent co-morbidities (HTN& DM) were detected among his study sample.

**In relation to family history**, the current results found that the majority of the studied patients had no family history for bladder cancer. This result is in line with *Abdel-Wahid, (2022)* who conducted "Nurse Led Intervention to Enhance Self-care Efficacy among Patients Undergoing Urinary Diversion at Urology and Nephrology Center- Mansoura University " pointed out that, the all patients in both groups had no family history of bladder cancer. .

**Concerning patients' knowledge and practice regarding urostomy care**, the findings of the present study showed that, the majority of the studied patients had unsatisfactory level of knowledge and urostomy self-care practice, This finding may be due to the high proportion of the studied patients live in rural areas that had lack of knowledge. In that context, *Chen, et al. (2020)* who stated that, Patients' knowledge may influence both self-care and self-efficacy, as poor knowledge regarding the condition may result in difficulty recognizing and evaluating symptoms, leading to poorer confidence (self-efficacy) in acting upon symptoms and less self-care.

Also this result agree with *Mahdy et al.,(2024)* who conducted a study about " Assessment of Self-Care Practice and Its Associated Variables among Colostomy Patients" reported that, most of the studied patients had inadequate practice, and 0% of patients had self-efficacy regarding colostomy care

**As regard to the quality of life of urostomy patients**, the findings of the present study showed that, the majority of the studied patients had sever disability of quality of life post-operative, This finding may be due to the high proportion of the studied patients live in rural areas, elderly and illiterate that had lack of knowledge and inadequate cope with stome . In that context, *Shaaban, et al.(2022)* who conducted a study about "effect of teaching package on awareness and quality of life among patients with cystectomy" reported that , most of the studied patients had poor health related quality of life.

The present study findings indicated that, there was a statistical significant positive correlation between knowledge score and practice score, which indicated that an increase in knowledge level will associated with an increase in practice level. The findings was supported by *Mahdy et al.,(2018)* illustrated that there were positive significant correlations between patients' knowledge, practice, and quality of life in a study entitled the effect on patients' self-efficacy and incidence of peristomal complications after permanent urostomy.

## Conclusion

Based on the current findings, it can be concluded that: unsatisfactory level of knowledge and unsatisfactory level of self-care practices and poor quality of life were reported by a high percent of participants.

## Recommendations

Based on the findings of the present study, the following are recommended:

- Implement self-care practice educational program regarding urostomy.
- Develop educational programs based on the Orem self-care model for patients with urostomy, focusing on enhancing self-care skills, effective ostomy management, and adaptive coping strategies.
- Simple booklet written in simple Arabic language recommended to developed, and be available for all patients with urostomy included all information about urostomy, quality of life and self-care.

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