



كلية الطب
والصيدلة - مراكش
FACULTÉ DE MÉDECINE
ET DE PHARMACIE - MARRAKECH

Year 2022

Thesis N° 312

Quality of life in patients after total cystoprostatectomy: Experience of Moroccan patients

THESIS

PRESENTED AND PUBLICLY DEFENDED ON 22/11/2022

BY

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Born on 16 May 1997 in Marrakech

TO OBTAIN THE DEGREE OF DOCTOR IN MEDICINE

KEYWORDS

Quality of Life-Bladder cancer-EORTC QLQ-C30/BLM30 questionnaires

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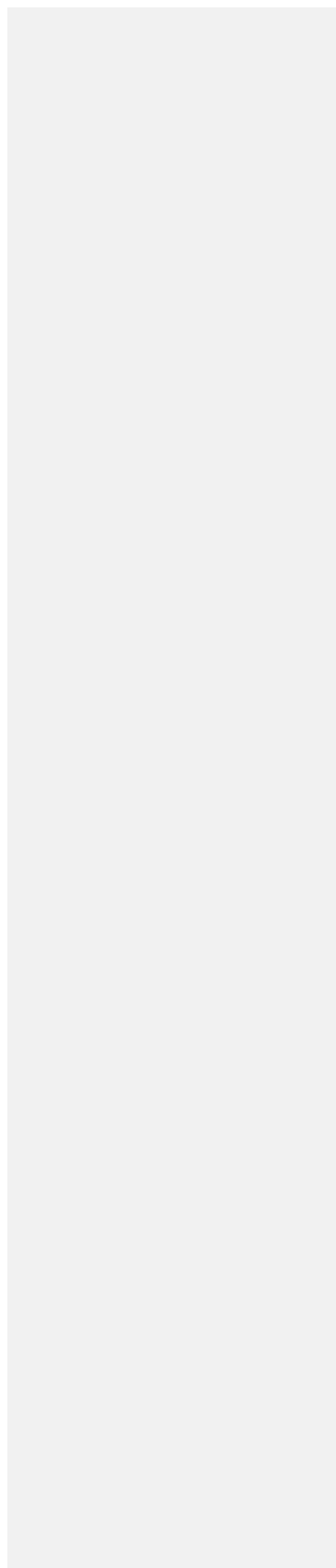
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JUDGES

بِسْمِ اللَّهِ الرَّحْمَنِ الرَّحِيمِ
اقْرَأْ بِاسْمِ رَبِّكَ الَّذِي خَلَقَ





HIPPOCRATIC OATH

AS A MEMBER OF THE MEDICAL PROFESSION:

I SOLEMNLY PLEDGE to dedicate my life to the service of humanity;

*THE HEALTH AND WELL-BEING OF MY PATIENT will be
my first consideration;*

*I WILL RESPECT the autonomy and dignity of my patient; I WILL MAINTAIN
the utmost respect for human life;*

*I WILL NOT PERMIT considerations of age, disease or disability, creed, ethnic
origin, gender, nationality, political affiliation, race, sexual orientation, social
standing, or any other factor to intervene between my duty and my patient; I
WILL RESPECT the secrets that are confided in me, even after the patient has
died;*

*I WILL PRACTISE my profession with conscience and dignity and in
accordance with good medical practice;*

I WILL FOSTER the honour and noble traditions of the medical profession;

*I WILL GIVE to my teachers, colleagues, and students the respect and gratitude
that is their due;*

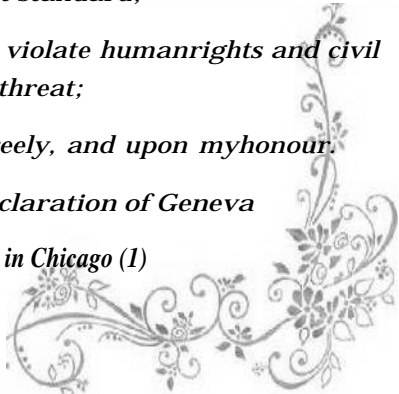
*I WILL SHARE my medical knowledge for the benefit of the patient and the
advancement of healthcare;*

*I WILL ATTEND TO my own health, well-being, and abilities in order to
provide care of the highest standard;*

*I WILL NOT USE my medical knowledge to violate human rights and civil
liberties, even under threat;*

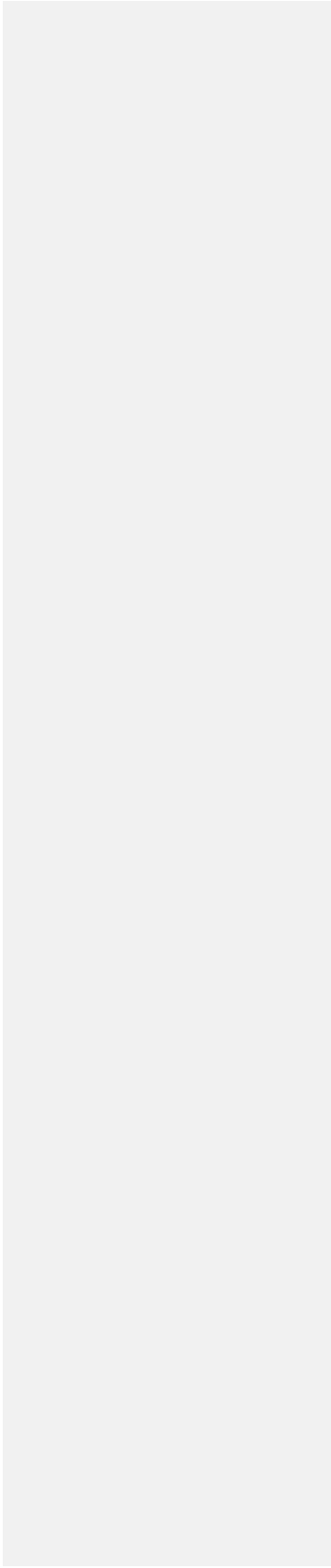
I MAKE THESE PROMISES solemnly, freely, and upon my honour.

*A newly revised version of the Declaration of Geneva
was adopted on October 14, 2017, in Chicago (1)*



The title is framed by four ornate, black-and-white floral corner ornaments. Each ornament is a complex, symmetrical design featuring swirling acanthus leaves, scrolls, and small floral motifs, arranged in a square pattern around the central text.

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Espace Après : 0 pt

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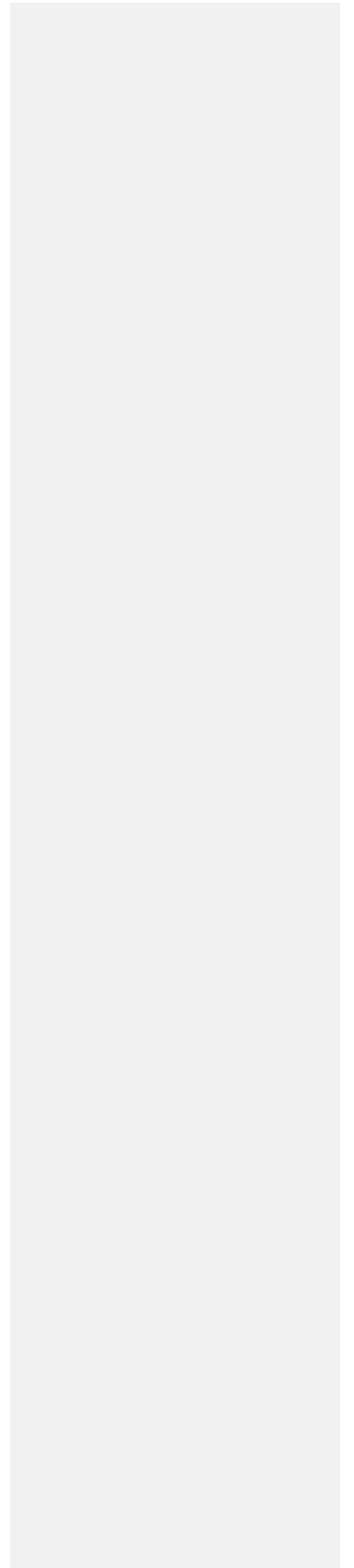
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CHETOUI Abdelkhalek	Cardiologie	RHEZALI Manal	Anesthésie- réanimation
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LISTE ARRÊTÉE LE 26/09/2022



DEDICATIONS





***-Wherever the art of medicine is
loved there is also a love of
humanity-***

Hippocrates

I dedicate this work to,

***In memory of my grand-parents:
Tamou Abid and Elmehdi Almagoussi***

*A little tribute to show that i remember. Time may pass and fade away
but memories of you wil stay. I wish we had more time together.*

May your souls rest in peace.

To my beloved parents Sofia Harraq and Abdelmajid Almagoussi,

*To whom i owe everything in life. I could have never done this without your faith
and support. Thank you for teaching me to believe in myself and in my dreams.*

*Thank you for making me the person i am today. Thank you for your love and
devotion. For all the sacrifices it took. For loving me, being patient with me. For
being there when i needed comfor, for easing my pain and sharing my
happiness. I am overly proud of being your daughter. I pray to God to keep you
by my side and to give me the strength to keep making you proud of me.*

I love you forever.

To my sister Salma,

*My best friend, my ride or die. To the dearest person i have. You shared my joys
and my pain. You made the bad days better and you made the good ones
magical. To the little girl i watched grow and bloom into this magnificent
woman. I hope that you too are proud of the person i became. There is no better
friend than a sister and there is no better sister than you.*

To lamiae,

*My cousin, my sister, my comfort person. You mean the world to me. You held me
in my bad times, you danced with me in my happiness. We traveled together in
life's journey. So here is to many more adventures. I love you with all my heart*

To my grandparents Fatima Ait Mouh and Mohammed Harraq

Lovely and kind, wise and strong. Your arms were always open no matter what i did wrong. You watched me grow and gave me your love, devotion and much more. To you i dedicate this work hoping i made you proud.

To my aunts, uncles and cousins

I could not be more happy to be a part of this family. Thank you for raising me, for being there every step of the way. I am overjoyed to have you in my life. The invisible threads that tie us as a family make for the strongest of bonds.

To Ichtiyak Amou

Long and beautiful years bring us together; words are not enough to express my feelings towards you, to all the moments that we spent together, all our laughter, our arguments and our nonsense, I am happy and lucky to call you my friend like you to hold on to in this roller coaster that we call life. Even when you are out of sight, you are in my heart, I admire your strength and your courage and I am proud of the woman you have become.

I know that we will always be there for each other.

Thank you for being the inspiring wonderful person you are.

To Hamza Benzakour

To all our laughter, to all our memories.

I thank you for your generosity and helpfulness.

You always listened attentively to me, and found the right words to comfort me. May God protect you and give you a flourishing future. May our bond grow stronger over the years and our friendship remain intact.

To Nizar Amlah

The bond that we have managed to forge throughout these years is not an ordinary one, it is the fruit of all our adventures, misadventures and especially our sincere friendship.

I thank you for your incomparable support and for your precious friendship. I am grateful to have known you and I hope that this friendship will last forever.

To Asma Amarai, Oumaima Aqbour, Amal Aoir, Hind Amlale, Sara Amimi Mohammed Reda Akernane, Montacer Ait Riala , Walid Ait Moha and Fahd Aljariri.

To the biggest blessing Medicine has given me, I can't imagine what this long journey would have been without you by my side. For our years of study, our first shifts. For all the games we played, all the memories we shared, for the laughter and joy you brought to my life. For your undying support, your kind hearts and your unwavering presence. You are more than friends to me. I can't find the words to express all my gratitude and love. I dedicate this work to you as a testimony of our friendship that I hope will last a lifetime.

To Assala Cherki, Jihane Hamdane, Saloua Hazmiri and Latifa Oumaiouf
I met you through our years of internship. I had the utmost pleasure to have discovered the amazing people you are. We had the sweetest moments and together we overcame many hardships. I will forever cherish the memories we made and i hope we will make a lot more. I love you very much

To Nidae Mimouni and Salaheddine Youbi

A beautiful encounter as one rarely has.

To all the good times spent together, to all our laughter and our memories.

I wish you a long life full of happiness and prosperity. I dedicate this work to you as a token of my gratitude, my love and my respect. Thank you for all the great moments we have shared. To many many more.

To my childhood friends Souad Cherqaoui and Lokman Mansouri

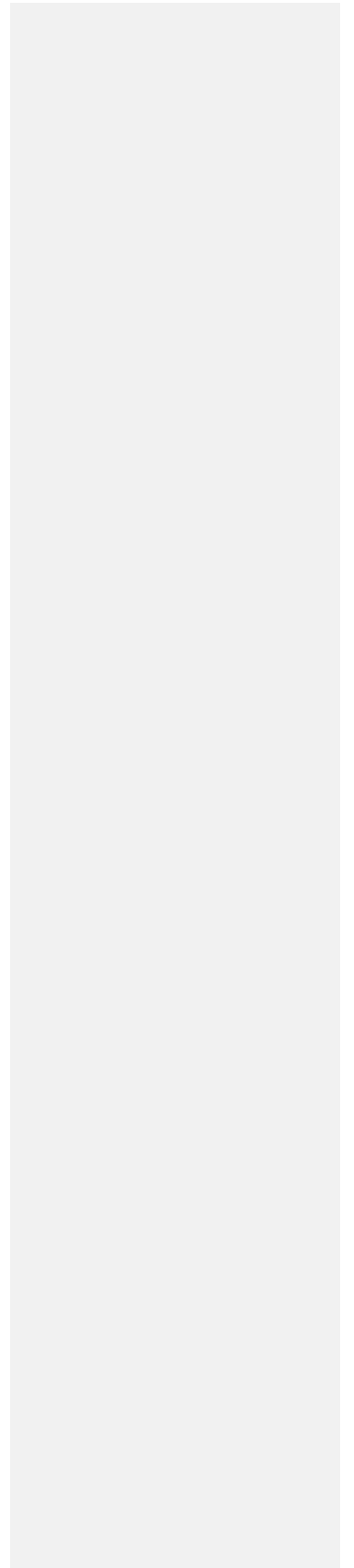
Thank you for the splendid moments we spent together. Thank you for the love and affection that you have always shown me, may they remain eternal.

Our paths may have separated but our friendship will remain forever.

*TO ALL THOSE WHO ARE DEAR TO ME AND WHOM I HAVE OMITTED TO MENTION
BUT WHOM I HAVE NOT FORGOTTEN. TO ALL THOSE WHO HAVE CONTRIBUTED IN
SOME WAY TO THE ELABORATION OF THIS WORK. MAY GOD BLESS YOU AND FILL
YOU WITH JOY*

Four ornate, black-and-white decorative corner ornaments are arranged in a square pattern around the central text. Each ornament features intricate scrollwork and floral motifs.

ACKNOWLEDGMENTS



To Professor Mohammed Zyani
Chairman of my thesis
Head of Internal medicine departement

I am very sensitive to the honor you have given me by kindly accepting to chair our thesis jury. You embody enviable social qualities: your kindness and your exemplary modesty combined with your professional and human skills will be an example for us in the exercise of our profession. Please find in this work, the testimony of my gratitude, my very high consideration and my deep respect.

To Professor Omar Ghoundale
Supervisor of my thesis
Head of Urology departement

It is impossible for me to say in a few words what I owe you. You have done me the great honor of entrusting me with this work and of accepting to direct it by devoting your precious time to perfect it. This work is the fruit of your efforts. I would like to thank you from the bottom of my heart and receive, dear master, my sincere feelings of gratitude, respect and deep sympathy. Thank you for all that you have done. Thank you for being so patient with me. I hope to be worthy of your trust, and I ask of you, dear Master, to accept my deep appreciation and high consideration.

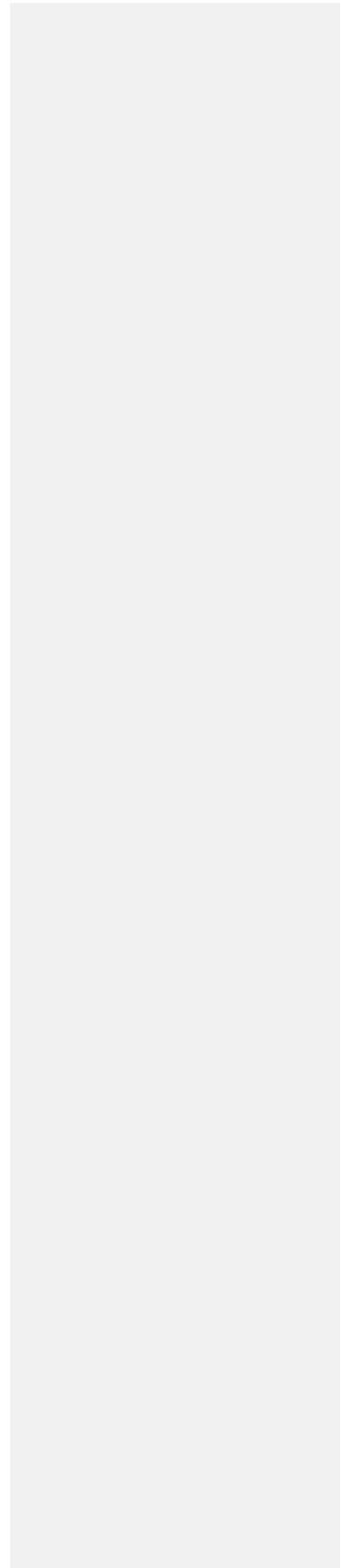
**To Professor Mohammed
Amine Laffinti
Judge of my thesis
Professor of Psychiatry**

I thank you for the spontaneity and simplicity with which you accepted to judge this work. Your probity at work and your dynamism, your sense of responsibility have always impressed me and are for me an ideal to reach.

Please find here, Professor, the expression of my sincere respect.

Four ornate, black-and-white decorative corner ornaments are arranged in a square pattern around the central text. Each ornament features intricate scrollwork and floral motifs.

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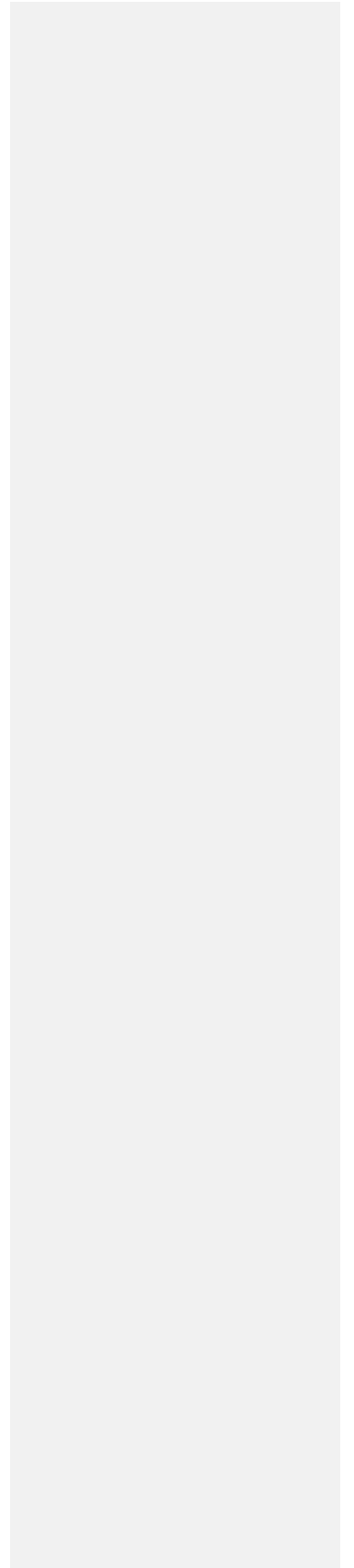
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ABBREVIATIONS



List of abbreviations

EAU	European Association of Urology
IC	Ileal conduit
ONB	Orthotopic neobladder
RC	Radical cystectomy
WHO	World Health Organization
QoL	Quality of life
HRQoL	Health-related quality of life
QALY	Quality-adjusted life-year
EORTC	Research and Treatment of Cancer
FLIC	Functional Living Index – Cancer
FACT-G	Functional Assessment Cancer Treatment
QLQ-C30	Quality of Life Questionnaire – Core 30
BCI	Bladder Cancer Index
EORTC BLM30	Muscle-Invasive Bladder Cancer Module
MCID	Minimal clinically important difference
MDC	Minimum detectable change
SEM	Standard error of measurement
SD	Standard deviation
PGI	Patient-Generated Index
SEIQoL	Schedule for the Evaluation of Individual Quality of Life
GLOBOCAN	Global Cancer Observatory
HDI	Human development index
GDP	Gross Domestic Product
IARC	International Agency for Research on Cancer
PNPCC2	National cancer plan 2020–2029
NCDs	Non communicable diseases
PROFILE	Patient Reported Outcomes Following Initial treatment and Long term Evaluation of Survivorship

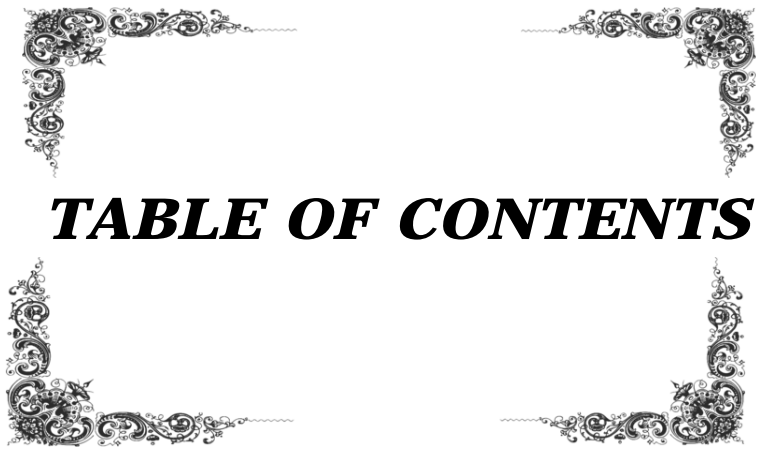
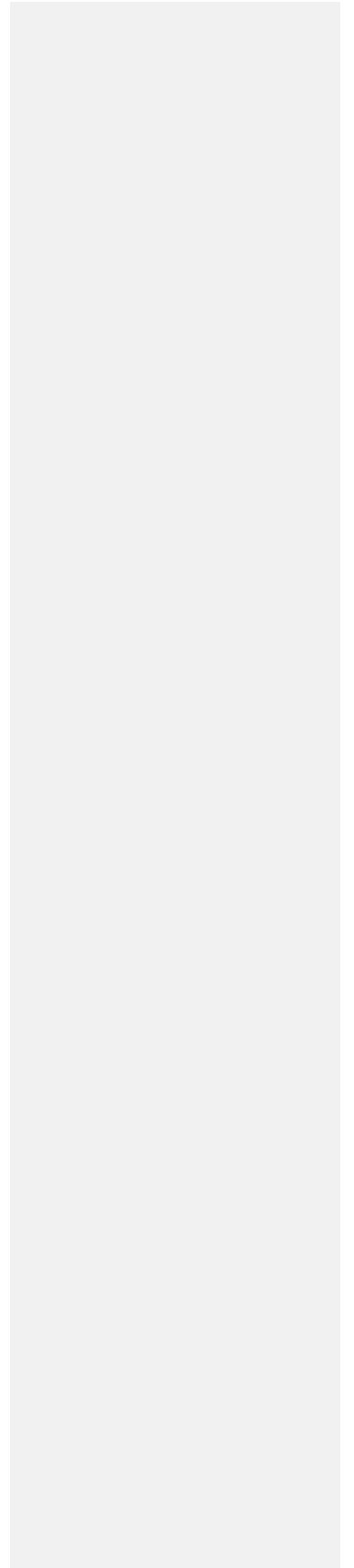
Four ornate, black-and-white decorative corner ornaments are arranged in a square pattern around the central text. Each ornament features intricate scrollwork and floral motifs.

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INTRODUCTION

Quality of life among patients after total cystoprostatectomy : perception of moroccan patients.

Cancer is the main health issue in the community across the world. Globally, cancer is one of the most common causes for morbidity and mortality [88].

Bladder cancer represents one of the most commonly diagnosed types of cancer [48]. It tends to be more common in men than women and its incidence increases with age. It mainly affects people over the age of 65 and is closely associated with smoking and exposure to certain chemicals [85].

Classically, according to the European Association of Urology (EAU) Guidelines, radical cystectomy (RC) represents the gold standard treatment for muscle-invasive bladder cancer. Unfortunately, no consensus has been reached about ideal age, timing and type of urinary diversion after radical cystectomy. Options range from ileal conduit (IC) to orthotopic neobladder (ONB) reconstruction, with different outcomes [48].

Although it leads to patient survival, this procedure has several consequences, including lengthening of the recovery period [85]. RC is associated with side effects such as erectile dysfunction and urinary incontinence, and also with considerable morbidity.

Complications related to radical cystectomy were found to be directly related to age, pre-existing comorbidities, as well as to the surgical procedure, bowel anastomosis, or urinary diversion [86]. Fear, distress and depression can add to the deteriorated quality of life. It is, therefore, essential to provide patients with appropriate nursing care, including pre- and postoperative counselling [85].

According to the World Health Organization (WHO), quality of life (QoL) is defined as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns." Understanding QoL involves addressing complex, multifactorial relationships covering a broad range of economic, sociocultural, and lifestyle factors. Stemming from the concept of QoL, the term health-related quality of life (HRQoL) has been coined to define the perception of individuals

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specifically regarding health aspects. The notion of HRQoL may be appropriate to evaluate the functional impact of medical conditions or health interventions on the lives of patients.

HRQoL is a useful measure for clinical, economic and policy-making settings. Not only is it widely employed as a primary patient-reported outcome in clinical research, it has also become an important part of routine clinical practice. Economic evaluations rely heavily on HRQoL as an outcome; one example is the quality-adjusted life-year (QALY), an effectiveness measure in cost-utility analysis. Because it is able to capture individual perceptions of physical and social well-being within the context of each population, HRQoL may serve as a guide for planning and evaluating health policies aimed at improving health and reducing inequity.

In addition to sociodemographic characteristics, such as gender, age, education, employment, and income, depression and a number of chronic diseases, such as heart failure, diabetes mellitus, and autoimmune diseases have been negatively associated with QoL [87].

Quality of life assessment is essential to better inform clinical decisions by providing information about the patient's experiences with disease and treatment.

Despite a number of potential benefits to both the clinician and the patient, patient-based measures of health have not been routinely or systematically used within routine practice by clinicians in the care of individual patients.

There are a number of practical, methodological and attitudinal barriers which have so far limited the use of patient-based measures of health within routine practice. The extent to which these barriers are overcome is likely to influence the effectiveness of such instruments in improving the process and outcomes of patient care.

To date, little attempt has been made systematically to review studies that have assessed the effectiveness of patient-based measures of health in routine practice in improving patient care and outcomes [78].

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In this work, we will try to review the concept of quality of life, its evaluation methods and the impact of different treatments on this quality, through a retrospective study, involving patients followed for invasive bladder cancer collected in the urology department of the military hospital Avicenne Marrakesh.



***MATERIALS
AND METHODS***

I. Type of study

Ours research is a descriptive retrospective study, conducted in the urology departement of the Avicienne Military Hospital of Marrakesh and it focuses on patients who were treated for invasive bladder cancer between the years 2017 to 2022.

II. Purpose of our research paper

The purpose of our study is to evaluate the quality of life in patients who underwent a radical cystoprostatectomy for invasive bladder cancer. Taking into consideration the impact on overall global quality of life but also the impact on specific daily tasks.

III. Selection of sample

Our sample included 15 patients.

1. Inclusion criterias

Were included in our study :

- ✓ Patients with invasive bladder cancer confirmed on pathology.
- ✓ Patients who underwent radical cystoprostaectomy.
- ✓ Patients diagnosed and treated between and 2017 to 2022.
- ✓ Patients who gave oral consent to participate in the study.

2. Exclusion criterias

Were excluded from our study :

- ✓ All non-autonomous patients with neurological or cognitive disorders that may severely impair their ability to correctly answer the questionnaires.
- ✓ Patients who did not give their oral consent.
- ✓ Patients with incomplete medical files (missing phone numbers, missing pathology reports,...).

IV. Course of the study

1.

Patients eligible for our study were interviewed either via phone calls or in-person interviews, depending on the patients' availability.

2. Data collection

To achieve our study we had access to :

- ❖ Hospitalisation charts
- ❖ Medical files of the Avicienne Military Hospital 's urology department

Each patient was interviewed anonymously and individually with the help of different valid surveys.

a) Sociodemographic related data :

The survey (annex 1) comprises three elements :

- ✓ Sociodemographic data
- ✓ Environmental data
- ✓ Clinical data

b) Quality of life related data :

To help us accomplish the goals of our research, information relevant to the quality of life has been measured by-way-of the European Organisation for Research and Treatment of Cancer (EORTC) questionnaires. (QLQ-C30, QLQ-BLM30).

- ✓ Questionnaire EORTC QLQ-C30 version3 (annex 2)
- ✓ Questionnaire EORTC QLQ-BLM30 (annex 3)

V. Ethical considerations

Recruitment of patients

To protect the confidentiality of our patients, the questionnaires were anonymous. The objectives and implications of our study were duly explained and the surveys were completed after oral consent was obtained.

VI. Statistical analysis

The QLQ-C30 is composed of both multi-item scales and single-item measures. These include five functional scales, three symptom scales, a global health status / QoL scale, and six single items.

Each of the multi-item scales includes a different set of items – no item occurs in more than one scale. All of the scales and single-item measures range in score from 0 to 100. A high scale score represents a higher response level.

Thus :

- a high score for a functional scale represents a *high or healthy level of functioning*,
- a high score for the global health status / QoL represents a *high QoL*,
- a high score for a symptom scale / item represents a *high level of symptomatology*.

The principle for scoring these scales is the same in all cases:

1. Estimate the average of the items that contribute to the scale; this is the *raw score*.
2. Use a linear transformation to standardise the raw score, so that scores range from 0 to 100; a higher score represents a higher ("better") level of functioning, or a higher ("worse") level of symptoms.

In practical terms, if items I_1, I_2, \dots, I_n are included in a scale, the procedure is as follows:

- Raw score

$$RawScore = RS(I_1) + RS(I_2) + \dots + RS(I_n)$$

- Linear transformation

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Apply the linear transformation to 0–100 to obtain the score S

- ❖ Functional scales: $S = \left\{ 1 - \left(\frac{RS-1}{Range} \right) \right\} * 100$
- ❖ Symptom scales / items: $S = \left(\frac{RS-1}{Range} \right) * 100$
- ❖ Global health status / QoL: $S = \left(\frac{RS-1}{Range} \right) * 100$

Range is the difference between the maximum possible value of *Raw Score* and the minimum possible value.

The QLQ-C30 has been designed so that all items in any scale take the same range of values. Therefore, the range of *Raw Scores* equals the range of the item values. Most items are scored 1 to 4, giving *range* = 3. The exceptions are the items contributing to the global health status / QoL, which are 7-point questions with *range* = 6.

The QLQ-BLM30 incorporates 6 Multi-item scales to assess Urinary symptoms and problems, Urostomy problems, Future perspective, Abdominal bloating and flatulence, Body image, and Sexual functioning. In addition, 1 Single item assesses Catheter use problems.

The scoring approach for the QLQ-BLM30 is identical in principle to that for the symptom scales of the QLQ-C30.

All of the Multi-item scales and Single-item measures range in score from 0 to 100. A high score for all of the Multi-item scales excluding Sexual functioning, and for the Single item, represents a high level of symptomatology or problems, whereas a high score for the Sexual functioning scale represents a high level of functioning.



RESULTS

I. Sociodemographic features

1. Age

The average age of our patients was of 64.4 years old with extremes varying from 54 to 73 years old [Figure 1].

The age range of 60 to 70 years old was the most affected (53%).

The age range of over 70 years old was the least affected (20%).

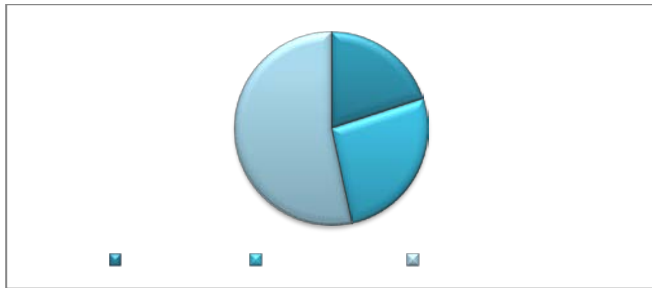


Figure 1 : Age distribution of patients

2. Marital status

Our study showed that 15 of our patients were married which represents 100% of the patients in our study.

3. Paternity

Our study showed that most of our patients (n=14) have children which represents 93.3% of the patients in our study [Figure 2].

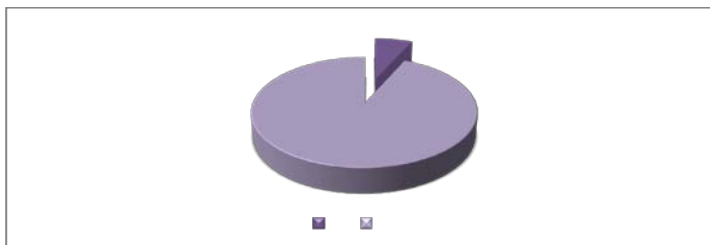


Figure 2: Distribution of patients by paternity.

4. Residence area

Ten of our patients (66%) were from an urban area and five (33%) were from a rural area [Figure 3].

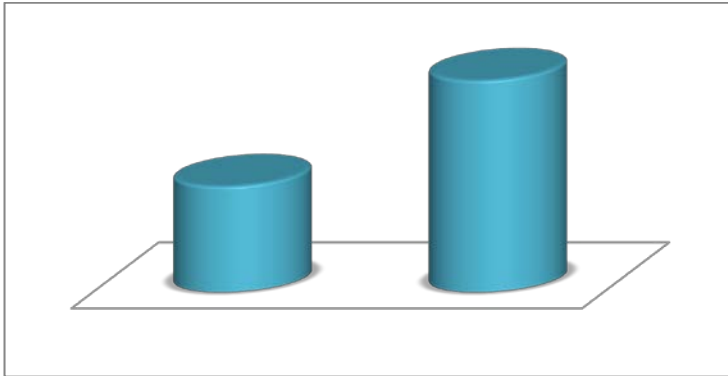


Figure 3 : Distrubtion by area of residence.

5. Socio-economical data

a)

Our research showed that all of our patients (100%) were retired.

b) Financial autonomy

We noted that 9 of our patients (60%) were financially autonomous versus 6 (40%) who needed financial support from their families [Figure 4].



Figure 4 : Distribution of patients based on financial autonomy.

c) Medical insurance

We noted that of 13 our patients (87%) have a medical insurance (FAR, CNOPS..) while 2(13%) were without one [Figure 5].

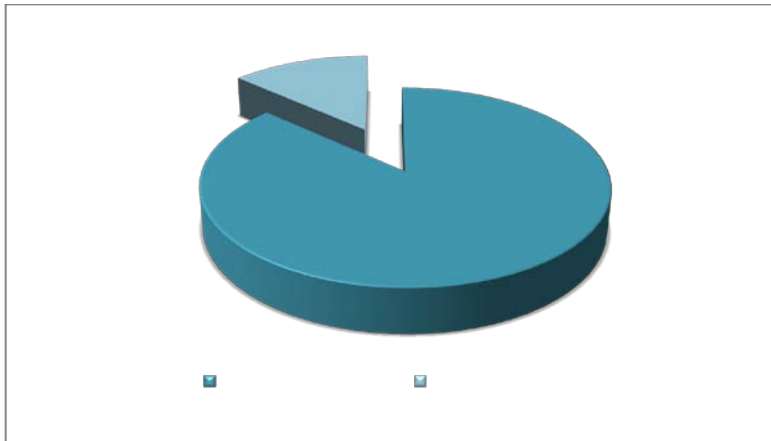


Figure 5 : Distribution of patients based on medical insurance.

II. Clinical features :

1. Frequency :

Our study showed that most patients (66%) were treated in the years 2018–2019[Figure 6].

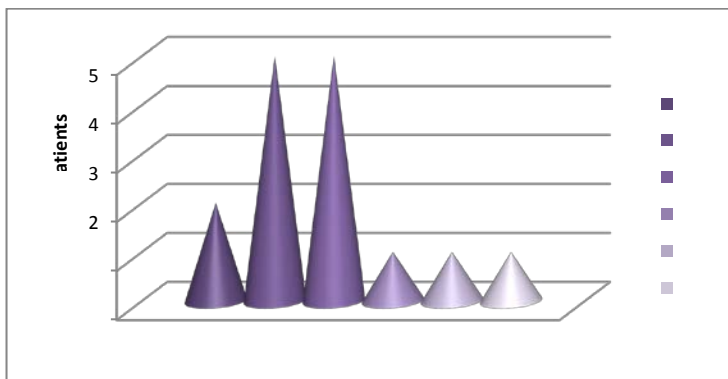


Figure 6 : Distribution of patients based on date of treatment.

2. Risk factors

We reported that 12 of our patients (80%) presented well known risk factors of bladder cancer while only 3 patients (20%) didnt have any risk factors [Figure 7].

The most common risk factor was revealed to be tobacco consumption (71%) followed by reccurent urinary tract infections (29%). The other risk factors were not found in any of our patients [Figure 8].

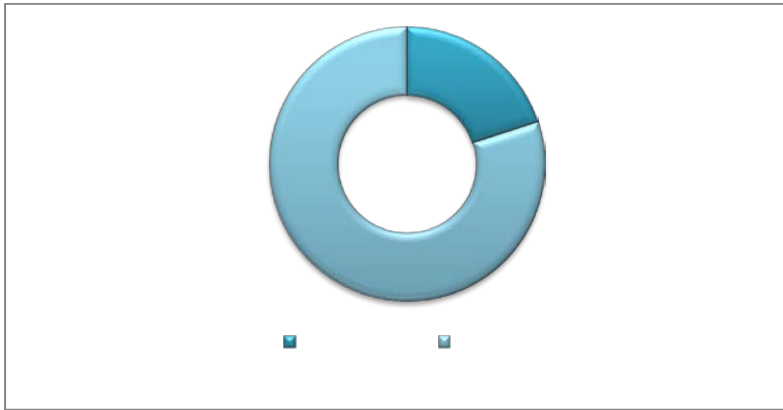


Figure 7 : Distribution of patients based on risk factors.

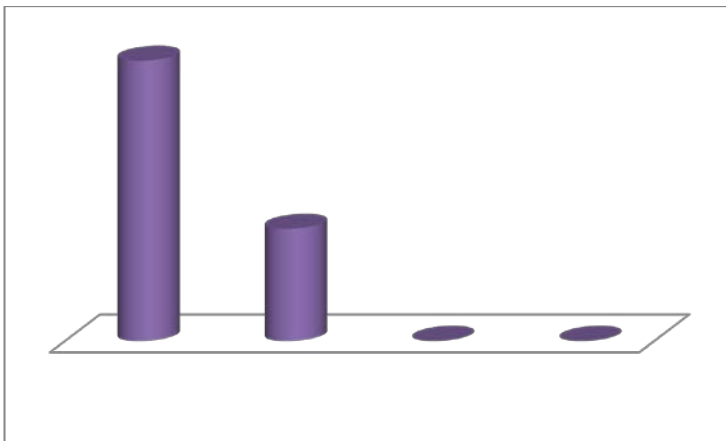


Figure 8 : Distribution of risk factors among patients.

3. Clinical background

a) Medical background

Our research showed that 5 of our patients (33%) had a medical history while 10 patients (67%) did not report any relevant medical history [Figure 9].

Out of the patients with medical history 2 had diabetes, one had hypertension, one had chronic nephritis and one had gout.

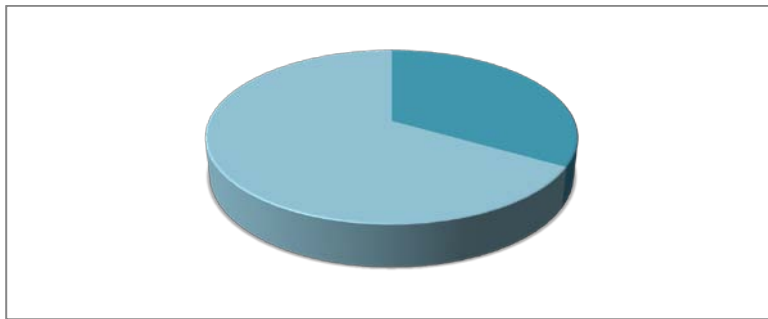


Figure 9 : Distribution of patients based on medical history.

b) Surgical background

Our research showed that 2 of our patients (13%) had a surgical history other than bladder cancer while 13 patients (87%) did not report any relevant surgical history [Figure 10].

Out of the patients with surgical history one had inguinal hernia and the other had lumbar surgery for sciatica.



Figure 10 : Distribution of patients based on surgical history.

c) Familial background

Our study showed that 3 of our patients (20%) had a family history of bladder cancer while 12 patients (80%) did not report any relevant family history regarding malignancies. [Figure 11]

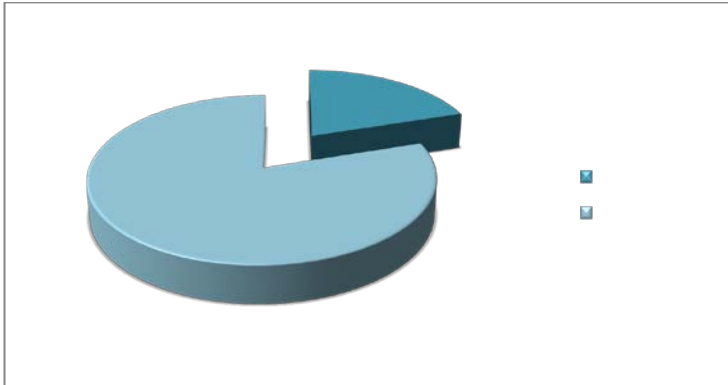


Figure 11 : Distribution of patients based on family history.

4. Patient management

a) Tumoral type

Twelve of our patients (80%) had invasive urothelial carcinoma on the pathology reports, two patients presented squamous cell carcinoma (13%) while one case of undifferentiated carcinoma (7%) was reported [Figure 12].

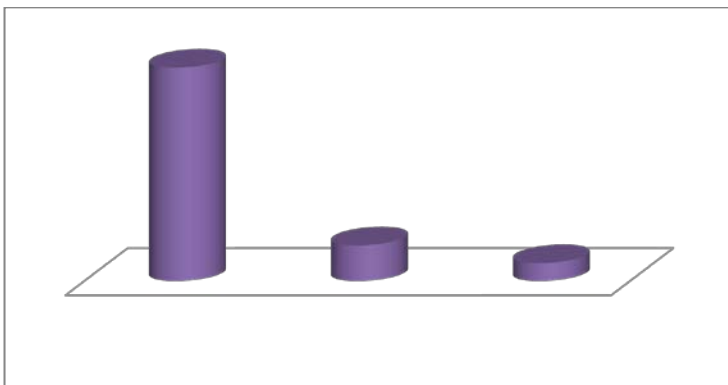


Figure 12 : Distribution of tumoral type among patients.

b) Tumoral stage :

Our study indicated that 10 patients (66%) had pT2 stage bladder cancer, 3 had pT3a stage bladder cancer (20%) while only 2 had pT3b stage bladder cancer (14%).

c) Surgical procedure :

Fourteen of our patients (93%) had underwent a Bricker ileal conduit diversion while only one of our patients benefited from a Studer orthotopic neobladder (7%) [Figure 13].

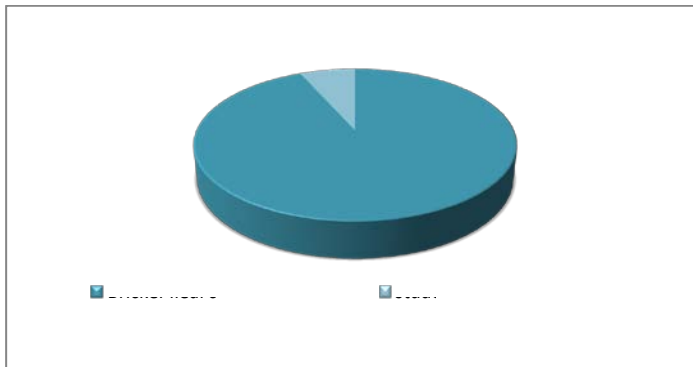


Figure 13 : Distribution of patients based on surgical procedure.



Figure 14 : Image of a patient with a urostomy after a Bricker ileal conduit [94].

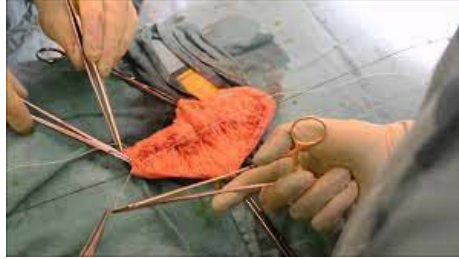


Figure 15 : Image of a patient with a Studer orthotopic neobladder [95].

d) Post-operative complications

We noted that 4 of our patients (27%) had a post operative complication while 11 (73%) did not present any complications [Figure 16].

The most common post operative complication was revealed to be sepsis (43%) followed by peritonitis, enterocutaneous fistula, wound infection and pelvic abscess. The other complications were not reported in any of our patients [Figure 17].

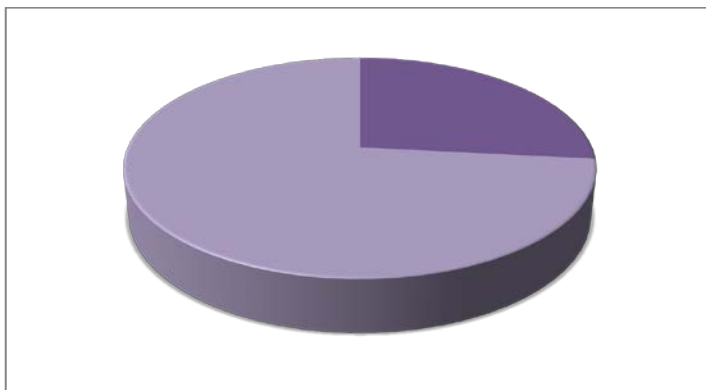


Figure 16 : Distribution of patients based on post operative complications.

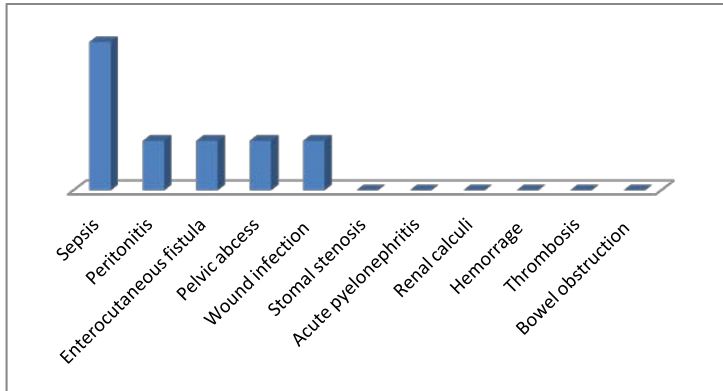


Figure 17 : Distribution of postoperative complications among patients.

III.

The QLQ-C30 Score is the EORTC's questionnaire related to the general quality of life of cancer patients. It is designed to be specific to cancer patients with a multidimensional structure. It associates five functional scales (physical, role, cognitive, emotional and social) to three symptom scales (fatigue, pain and nausea/vomiting) and a single global health status with an umbrella of single items assessing a variety of symptoms frequently reported by cancer patients .

In our study, we calculated the different scores of each item available on the EORTC QLQ-C30 questionnaire for each patient. We then proceeded to determine the means and standard deviation of each item as shown in [Table I].

Our estimation shows that in average, the global health score of our patients is 58,77. Concerning the functional scales, our patients scored the highest in terms of physical functioning with an average score of 88,46, while the social functioning was last averaging a 51,03 score. In the matter of symptom scales, our patients had the least trouble with diarrhea symptoms with an average score of 0, while they struggled most with financial difficulties (55,32), followed by insomnia (28,81) and fatigue (20,25) [Figure 18] [Figure 19].

Table I : Mean EORTC QLQ-C30 scores across the multiple items of our patients.

Scale	Mean (standard deviation)
Global health	58,77(±35,7)
Functional scales	
Physical functioning	88,46(±20,18)
Role functioning	68,88(±32)
Emotional functioning	63,31(±36,25)
Cognitive functioning	85,46(±23,57)
Social functioning	51,03(±40,12)
Symptom scales	
Fatigue	20,52(±31,18)
Nausea	14,37(±29,97)
EORTC QLQ C30 SCORE Pain	16,59(±27,36)
Dyspnea	19,9(±30,29)
Insomnia	28,81(±37,45)
Appetite loss	15,52(±30,49)
Constipation	13,28(±30,25)
Diarrhea	0
Financial difficulties	55,32(±32,54)

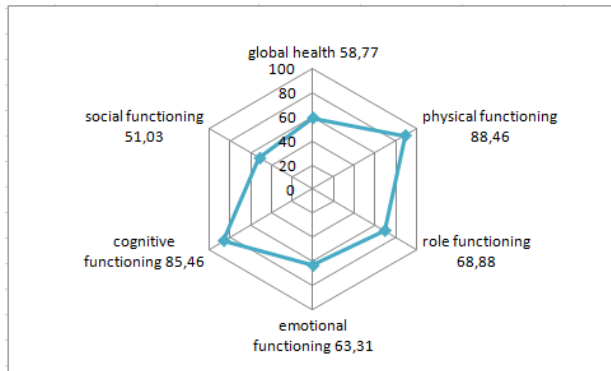


Figure 18 : Distribution of global health and functional scales scores.

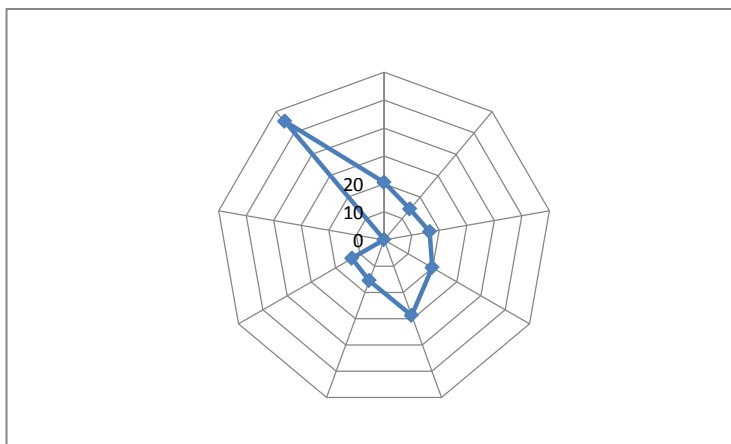


Figure 19 : Distribution of symptom scales scores.

IV. EORTC BLM30 SCORE :

The BLM30 Score is the EORTC's questionnaire formulated specifically for invasive bladder cancer patients. It incorporates 6 Multi-item scales to assess Urinary symptoms and problems, Urostomy problems, Future perspective, Abdominal bloating and Flatulence, Body image, and Sexual functioning.

In our study, we calculated the different scores of each item available on the EORTC BLM30 questionnaire for each patient. The means and standard deviation of each item were then established [Table II].

Table II : Mean EORTC BLM30 scores across the multiple items of our patients.

Scale	Mean (standard deviation)
Urostomy problems	39,48 (\mp 23,14)
Future perspective	45,45 (\mp 30,36)
Abdominal problems	8,88 (\mp 26,66)
Body image	41,85 (\mp 33,05)
Sexual concerns	42,72 (\mp 12,87)

Our estimation shows that in average, our patients struggled more with future perspective problems with a mean score of 45, 45, followed by sexual concerns (such a erection problems, ejaculation problems, decrease in libido...) with an average score of 42,72. Body image concerns and urostomy problems were common amongst our patients, totaling scores of 41,85 and 39,48 respectively. Abdominal problems such as flatulence and bloating did not constitute a major problem in our patients daily lives with a low average score of 8,88 [Figure 20].

Quality of life among patients after total cystoprostatectomy : perception of moroccan patients.

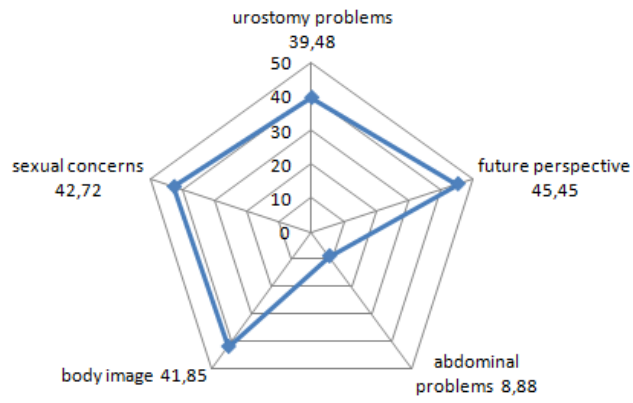


Figure 20 : Distribution of EORTC BLM30 scales scores.

Four decorative corner ornaments, each featuring intricate scrollwork and floral patterns, arranged in a square formation around the central text.

DISCUSSION

I. General aspects of QoL

Quality of life is a vague concept defined and measured in many different ways. It has become a label for distinct research traditions within health economics, medical sociology and psychology [1]. With time, it progressed to a relatively precise, operationally defined, patient–outcome measure. The concept has developed from some vague notions, empirically applied, to the point at which the paradigm has substantial foundations [2].

In trying to work out a pragmatic definition, one must also take into account people's individuality and the daily fluctuations in their abilities, inclinations, and aspirations. Is there some overall ephemeral, single number that can be used to represent "quality of life"[2]?

Although there is a general consensus on the paradigm, this question has not been resolved and it will continue to be asked as more experience is gained [2].

1. Definition

Quality of life (QoL) ; a multidimensional, dynamic, and subjective concept ; is difficult to define and measure. It is a concept that is both complex and elusive, and is recognized to be imperfect. Although, agreement about a definition of QoL is lacking, there is a consensus that QoL is related to a subjective sense of well-being [3].

One of the first attempts at defining QoL was the work of E.M. Gerson [4] who defined it as the degree to which an individual succeeds in accomplishing his or her desires. And the work of, Colman [5] who considers that QoL is determined by the difference or the gap between the hopes and expectations of an individual and that individual's present experience.

Subsequently, Schipper [2] suggested a more comprehensive take on the concept of QoL. He defined it as patient centered and functional. It represents an aggregate of day–to–day capacity across four areas: physical and occupational, psychological, social interactions and somatic sensation. It is designed to use patients as their own internal controls and by that tactic

achieves the strategic goal of being able to compare treatments for which psychological and demographic homogeneity within groups cannot be achieved [2].

Meanwhile, according to the World Health Organization (WHO), QoL is an individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. It is a broad-ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs, and their relationship to salient features of their environment [6].

In recent years, the topic of QoL continued to gain importance in the daily life of physicians, many of which tried to come up with an exhaustive definition to the concept. D.G.Willis and al [7], considered; "individuals' quality of life to be based on their values, beliefs, and meanings related to life experiences".

Meanwhile the latest definition was that of Roy who characterized QoL as "the value and significance that individuals ascribe to their lives within their changing situations" [9].

2. Dimensionality of the construct

QoL has become a key concept for evaluating the quality and outcome of health care, especially in chronic disease. But, despite this attention, there is limited consensus on the definition of the term. In fact, there is considerable confusion in literature regarding the definition and the use of the QoL concept [10].

To try and remedy to this confusion, researchers have tried to determine the different dimensions representing the architecture of QoL.

According to Schipper QoL is comprised of four principal dimensions [2]:

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- a) *Physical and occupational function* is meant to represent people's task-oriented function. At lower levels of function and purposefulness, it encompasses self-care efforts and the physical and intellectual effort of getting things done, at home or in the community.
- b) *Psychological function* describes one's overall mental state. Anxiety, fear, and depression are concomitants of illness, cancer in particular, that profoundly influence the overall quality of life. They are not, however, the sole attributes of psychological function. Other attributes, including the sense of well-being or hope, as well as the more dissociative factors, such as denial and psychosis, clearly may influence one's perceptions of one's quality of life.
- c) *Social interaction* describes people's societal functioning. It is a measure of the net effect of an individual's desire for and ability to make contact with other individuals and to be part of the community. The social interaction component need not represent purposeful interactions. It can reflect the most casual social contact, as well as contacts that are strictly goal oriented.
- d) *Somatic sensation* is different from the other three components. It is designed to provide a sense of how much pain, nausea, or other noxious sensations are part of a patient's day-to-day existence and the effect that these sensations have on the overall quality of the patient's life.

Different other authors approached QoL based on distinct but similar dimensions, such as physical, social, and psychological [8 ; 19 ; 20 ; 21; 22].



Figure 21 : The different dimensions of QoL.

Balance among multidimensional factors is needed for positive QoL. It has attributes that relate to multidimensional balance including the ability to perform physical, social, and occupational activities. These studies provide some indication that positive QoL is a result of balance among different dimensions [11].

Roy discussed health as more than the absence of disease but rather the integration of processes that keep the system in balance as well as the state of balance that is considered adaptation [12].

Not only is positive QoL a result of balance in dimensions, it is also the ability to adapt and cope during disturbances in these dimensions. He also considered adaptation critical in the four adaptive modes (physiologic mode, role function mode, interdependence mode and self-concept mode) through subsystems: the regulator that controls major physical systems and the cognator through which more psychological and emotive systems are controlled[12].

Roy illustrated the importance of balance among dimensions and in each mode, as shown in the figure below. The prism shows that an optimal QoL does not mean being extremely positive in one dimension and negative in other dimensions but obtaining balance among different dimensions [12].

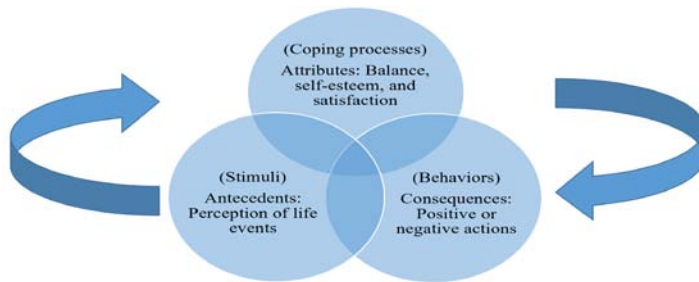


Figure 22. Quality of Life a Continuous Cycle Through the Prism of Roy [12].

II. Measurement tools

QoL emerges as a multidimensional concept, including physical, psychological, and social domains.

In fact, though QoL is a concept that embraces the entirety of people's lives; health seems to be a fundamental aspect of its definition [10].

QoL may be measured in clinical practice for several reasons: to assess the impact of a disease or condition, to assess the impact of a medical or surgical intervention, to profile a population, to assess the relationship between QoL and prognosis or health outcome, to improve communication, to screen for risk, to identify preferences, to train new staff, and for use in clinical audit and in clinical governance .

The measurement of QoL is useful for clinical practice beyond research purposes. QoL tools are important patient-reported outcome measures and useful in achieving or optimising patient centred care [89].

1. Construction of a quality of life instrument.

QoL is a subjective concept; thus it is appropriate to assess perceived QoL rather than to obtain a more objective evaluation. QoL also is a multi-dimensional concept, and there is considerable agreement that assessment of QoL should cover ; at minimum ; physical, psychological and social dimension [32].

The development and selection of measures used to assess quality of life issues are influenced by the purpose and design of the study, and by the age group under consideration [32]. To construct a QoL instrument a multitude of questions must be answered and different criterias must be met, here we will overview the basic standards necessary to complete a QoL instrument.

According to Aaronson [33], in order to establish a QoL instrument these questions must be answered:

a) *Who should assess quality of life?*

The quality of life of patients can be assessed by a health care provider, by the patient, or by someone close to the patient such as a partner or other family member.

Historically, it has most often been the physician who has provided such assessments, albeit in a limited way. The principal advantages associated with such clinician-based observation techniques are of a practical nature.

Nevertheless, methodologic limitations exist with certain physician rating scales and may outweigh their practical advantages.

In light of these considerations, it is increasingly argued that it is desirable, and often necessary, to ask patients directly about the impact of disease and treatment on their daily lives.

Feedback provided by a family member can also yield useful information regarding the patient's quality of life.

b) *What should be assessed?*

Quality of life is most often approached as *multidimensional* construct composed minimally of the following four domains:

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- Physical functional status
- Disease-related and treatment-related physical symptoms
- Psychologic functioning
- Social functioning

Beyond this core set of domains, additional psychosocial topics are often included in assessment batteries that are of relevance to particular patient populations (e.g., sexuality and body image, cognitive impairment, fear of disease recurrence, etc.).

Working within such a multidimensional framework, the researcher must strike a balance between breadth and depth of coverage. Instruments designed to measure a wide spectrum of quality of life dimensions can typically address each topic only on a relatively superficial level. Other measures focusing on a narrower range of issues can offer greater depth of inquiry per topic.

c) *Should quality of life measures be generic or disease specific?*

Quality of life measures can be organized along a continuum reflecting their intended spectrum of application:

- *Generic* measures designed for use across a broad range of chronic disease populations.
- *Disease-cluster* instruments that have a somewhat narrower focus, while still maintaining a generic element (e.g, measures designed for use with cardiovascular disease or for cancer populations, in general).
- *Disease-specific* measures (e.g, designed for primary breast cancer patients, essential hypertension patients, etc.).
- *Ad hoc* measures designed for a specific study.

The principal advantage associated with the more generic class of measures is that they permit comparison of results across studies, a feature that is of particular relevance in this age of meta-analysis.

The major limitation of such generic measures is that they may not address topics of particular relevance for a given disease or treatment (e.g., specific disease symptoms or treatment side effects).

Conversely, although more disease- oriented measures offer a greater degree of specificity, this is often achieved at the expense of generalizability.

d) What psychometric properties should be considered in evaluation of a questionnaire assessing quality of life?

A central consideration in choosing among candidate quality of life measures is the extent to which psychometric standards of reliability, validity, and sensitivity are met.

Reliability refers to the extent to which a measure or instrument yields the same results when used on repeated trials. The consistency with which an instrument or scale provides the same results thus describes how reliable the scale is. Several approaches to reliability testing are available [36].

Reliability is often best determined by internal consistency estimates. This correlational technique indicates the extent to which the hypothesized scales are free of random error. Other approaches to reliability testing such as the test-retest method and interrater comparisons may be less useful in examining the performance characteristics of questionnaires used in clinical trials [33].

Validity refers to the extent to which an instrument measures the concept it is intended to measure [36]. Although examination of the face validity of scale items does not involve any formal statistical procedures, it represents one of the most important steps in the validation process. In order to maximize the face validity of quality of life measures, it is useful to include a range of individuals (e.g, physicians, social scientists, methodologists, and patients) both at the stage of item construction and during pretesting. *Criterion* validity involves testing a scale against some other empirical standard. Unfortunately, in quality of life research it is often difficult to identify criterion measures that are themselves valid and reliable (e.g, for assessing psychologic or social dysfunctioning) [33].

The sensitivity of an instrument to either intraindividual change over time or interindividual differences is an essential consideration in clinical trial based quality of life research. In comparative studies, the degree of sensitivity demanded of an instrument is inversely related to the expected effect size (i.e., the magnitude of change or differences in quality of life parameters that one is interested in detecting) [33].

2. Types of tools

a) Open interview

Interviews represent perhaps the most flexible means of collecting patient based quality of life data. They can be applied to the broadest range of patients, including those who would otherwise be unable to complete a self-administered questionnaire (e.g, the elderly, the poorly educated, the physically handicapped) [33].

Interviews also facilitate sophisticated question branching and can minimize the problem of missing data by incorporating probes for clarification or amplification of patients' responses. Offsetting these advantages is the fact that interviews require more commitment of staff time than is typically available in clinical settings. Particularly in multicenter clinical trials, it cannot be expected that sufficient resources will be available to permit interviewing as the standard means of data collection [33].

b) Psychometric tests

The psychometric tools allow for standardized results which makes them equatable. Two types of psychometric tools exist : general tools to compare the QoL of patients independently from personal characteristics, and specific tools catered toward certain conditions for example the impact of a disease or its treatment on the QoL [13].

III. Practical measure of quality of life

QoL is a dynamic multidimensional construct that changes over time and can be modified by age and experience.

One aspect of QoL often measured within clinical settings is health-related quality of life (HRQoL), the most commonly used framework to assess the impact of illness and an important component of survival.

The range of domains assessed by HRQoL measures includes physical function, symptoms, global judgement of health, psychological and social well-being, cognitive functioning, role activities, personal constructs, and satisfaction with care . This is just one aspect of QoL, however, which also includes non- health-related domains such as work, family, friends, spirituality, and other life circumstances. It is important to define QoL and the domains of interest before selecting measures to evaluate it [13].

Ideally, to intergrate a questionnaire to a day to day practice, it needs to be easy to understand and carry out, it also needs to be concise, reliable and capable of measuring a significant change with clinical sense to the patient [13].

The systematic and repeated use of QoL questionnaires proved its place in the communication between healthcare professionals and their patients, its importance in patient management issues and teh optimization of treatment adherence as well as the patient's satisfaction withn the care provided [13].

1. Choice of measurment instrument

What is the most appropriate instrument to use? The choice of instrument may be crucial to the success of a study and many questionnaires exist, not all of which have been extensively validated. Extensive reviews of general and disease-specific questionnaires exist. The choice of instrument must be made with care, and expert advice is important [34].

The use of a questionnaire relevant to health-related quality of life as an endpoint must meet several requirements [13]:

- be validated (measure what it is supposed to measure) for a specific organ/disease and/or patient management;
- be reliable (between raters, internal consistency), i.e., give the same results when there has been no real change;
- have relevance in daily management at the individual and population levels;
- have prognostic value for health-related quality of life and be related to other clinical criteria.

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- Higginson and Carr [90] outline a set of 10 questions to ask when assessing any QoL measure for use within a clinical practice as shown in [Figure 23]. These include questions related to the domains covered within the measure, the development and testing of the measure, the psychometric properties of the measure, the assumptions of the assessors when determining validity, the sensitivity of the measure over time, the application and procedures for use of the measure, the intended audience, and the training and information needs related to the measure.

For QoL assessments, the aims should be clear and the item contents of the measure should be relevant and appropriate to the study. The instrument should have good psychometric properties (reliability, validity, and responsiveness) and must be familiar to the investigator. The psychometric properties may vary between population groups with different cultural values or languages. Guidance should be sought from experts in the field before its use, and copyright requirements including payment of any royalty fee considered [89].

There are two basic types of measure of health-related quality of life (HRQoL) generic and disease/population specific. Deciding which to develop will be dependent on the aims, methodological concerns, and practical constraints of the investigation.

Generic measures summarize a spectrum of domains and dimensions of health that apply equally and broadly to diverse conditions or populations, and usually contain the domains of physical, mental, and social health [14].

Disease or population specific measures contain domains and dimensions that are designed to be valid only for a specified condition or population. Disease specific measures, therefore, maximise content validity and provide for greater sensitivity and specificity; however they cannot be used to compare HRQoL across conditions or populations (including control groups from the general population) and may be less relevant for measuring the general HRQoL of the target condition/ population [14].

Generic instruments and specific instruments are often used in combination to provide information about the range and magnitude of treatment effects on HRQoL. This information is

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helpful in measuring the health of populations, assessing the effectiveness of clinical trials and rehabilitation services, and providing information for health care policy decisions [15].

The psychometric approach places heavy emphasis upon an individual's response and response variability across individuals. An important contribution of the psychometric approach is that it provides measurement of subjective or perceived well-being. Psychometric measures may or may not include a summary or total score [16].

In contrast to the psychometric approach, the utility approach is explicitly concerned with decisions about treatment, usually at a policy level. In this approach, treatments are typically evaluated for their benefit compared in some way to their cost. The utility approach to health status measurement evolved from a tradition of cost/benefit analysis, into cost/effectiveness approaches and, most recently, cost/utility approaches [16].

Neither approach alone is sufficient to understand clinical trial outcome data. The psychometric approach provides a detailed perspective of the patient, but it does not generally tell us how important a given problem or set of problems is to a group of patients. The utility approach informs us about the relative value of various health states; however, because of its emphasis on a single summary score, it fails to reflect the specific problems that might emerge [16].

Generic and specific measures each have their own strengths and limitations. The assessor must select the measure most appropriate to the question of interest. Generic instruments permit the simultaneous measurement of different domains of QoL and therefore reduce measurement burden. However, these might not be the domains of QoL of interest to the assessor or the patient [89].

They also allow for comparison of interventions across different diseases and different populations. However, they may not be responsive to small but clinically important changes.

Specific measures offer the potential for increased responsiveness and often focus on areas routinely explored by clinicians. They can be specific to a number of different factors such as disease, population, function, and given condition or problem that may be caused by underlying disease. They are not designed to be comprehensive, however, and they cannot be used for comparison between conditions [89].

As discussed earlier, the assessor should clearly define QoL and identify the domains of interest to inform the decision of which instrument to use. This decision should also be justified in any subsequent reporting of the study

In addition to reporting the process that led to the selection of QoL measures, participants must receive explicit instructions so they understand whether they are being asked to rate overall QoL, general HRQoL, or diseasespecific QoL [89].

-
1. Are the domains covered relevant?
 2. In what population and setting was it developed and tested, and are these similar to those situations in which it is planned to be used?
 3. Is the measure valid, reliable, responsive, and appropriate?
 4. What were the assumptions of the assessors when determining validity?
 5. Are there floor and ceiling effect—that is, does the measure fail to identify deterioration in patients who already have a poor quality of life or improvement in patients who already have a good quality of life?
 6. Will it measure differences between patients or over time and to what extent?
 7. Who completes the measure: patients, their family, or a professional? What effect will this have—that is, will they complete it?
 8. How long does the measure take to complete?
 9. Do staff and patients find it easy to use?
 10. Who will need to be trained and informed about the measure?

Figure 23 : Questions to ask when choosing a QoL measure [15].

2. Analysis and interpretation of results

To be an appropriate clinical tool, the measure must be suitable for its intended use. The results from the test must be valid, reliable, and accurate.

Reliability in an HRQoL test means that stable patients would give the same response after repeated administration [15].

Accuracy in an HRQoL test means that the instrument is responsive and able to detect small longitudinal changes. These instruments must also be interpretable and sensitive enough to distinguish whether changes in their role or function is trivial, small, moderate, or large [15].

The validity of any measure of QoL is clearly vital. It is important to know that we are measuring what we think we are measuring, but this is more complex than generally assumed. It is common to read that a measure is “valid” where the emphasis is on empirical validity or the extent to which the measure correlates with related phenomena [17].

A critical misassumption is that validity is a property of a measure; in fact, validity is only inferred from the assumptions about individuals that are drawn from the scores obtained. There is no gold standard. Misunderstandings about definitions of validity and the implications for measuring QoL continue to create a barrier to clinical and research use [17].

IV. Use of quality of life tools in oncology

The quality of life tool enables us to evaluate a given treatment not only with regard to its effect on pain intensity but also with regard to its overall impact on the total individual.

The use of quality of life as a measure of outcome in pain research enables the investigator to focus on the patient [18].

1. Different available QoL questionnaires

Quality of life questionnaires can be classified according to their field of application. A distinction is made between generic and specific questionnaires.

a) Generic QoL questionnaires

These are the first quality of life questionnaires to have been developed, most of them in English. They are intended for the general population or for a population of patients, whatever the disease and the degree of severity. They allow comparisons between healthy and sick subjects. But their major disadvantage is their reduced capacity to detect changes over time.

One of the first questionnaires to be developed was the *SICKNESS IMPACT PROFILE* in 1976, by Bergner and al [68], it comprises 14 items covering subjects from social interaction, to personal hygiene and emotional well-being [58]. The Nottingham health profile was developed by Hunt and al in England in 1981 [69], it includes six packages referring to different areas of functioning like pain, physical mobility, energy and social isolation [59].

Later on, a multitude of other questionnaires were constructed, the most used ones are the *SF-36 health questionnaire*; which is a self-administered questionnaire containing 36 items. It measures health on eight multi-item dimensions, covering functional status, well-being, and overall evaluation of health [60]; and the *European Quality Of Life-5 Dimensions (EuroQoL5D)* which includes 5 different items [70].

b) Specific questionnaires

Specific questionnaires have been developed for specific conditions. They allow a more precise exploration of the alterations specific to the disease and thus are more sensitive to change than generic questionnaires. The downside is that they do not allow comparisons with other diseases or other populations.

Certain tools quickly became established, such as the Functional Living Index - Cancer (FLIC) [71] in the United States, followed by the Functional Assessment Cancer Treatment (FACT-G) [72] and, in Europe, the Quality of Life Questionnaire - Core 30 (QLQ-C30) developed by the EORTC Quality of Life Study Group.

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In 1980, the EORTC created the Quality of Life Group, which in 1986 initiated a research programme to develop an integrated, modular approach for evaluating the QoL of patients participating in cancer clinical trials. This led to the development of the EORTC QLQ-C30, a quality of life instrument for cancer patients [23].

The QLQ-C30 is a 30-item questionnaire composed of both multi-item scales and single-item measures. These include five functional scales, three symptom scales, a global health status / QoL scale, and six single items. Each of the multi-item scales includes a different set of items – no item occurs in more than one scale [23].

All of the scales and single-item measures range in score from 0 to 100. A high scale score represents a higher response level. Thus a high score for a functional scale represents a high / healthy level of functioning, a high score for the global health status / QoL represents a high QoL, but a high score for a symptom scale / item represents a high level of symptomatology / problems [23].

There has been multiple versions of this questionnaire the latest of which is the EORTC QLQ-C30 3.0 and it is the one used in our study.

2. Specific questionnaires for bladder cancer

In terms of bladder cancer, there are approximately 11 specific quality of life questionnaires designed by multiple authors. Two of the most used questionnaires are the bladder cancer index and EORTC BLM30.

The Bladder Cancer Index (BCI) was developed in the United States (2007), and it contains neutral questions regarding native or neo-bladder, urinary diversion method, and gender. It is therefore comprehensive across a wide range of bladder cancer patients, independent of tumor infiltration and treatment applied [73,74].

The Muscle-Invasive Bladder Cancer Module (EORTC BLM30) is a supplementary questionnaire module to be employed in conjunction with the QLQ-C30. The QLQ-BLM30 incorporates 6 Multi-item scales to assess Urinary symptoms and problems, Urostomy problems,

Future perspective, Abdominal bloating and flatulence, Body image, and Sexual functioning. In addition, 1 Single item assesses Catheter use problems [24].

3. Minimal clinically significant difference

a) Definition

When assessing the clinical utility of therapies intended to improve subjective outcomes, the amount of improvement that is important to patients must be determined.

The smallest benefit of value to patients is called the minimal clinically important difference (MCID). It is the smallest difference in score in the domain of interest which patients perceive as beneficial and which would mandate, in the absence of troublesome side effects and excessive cost, a change in the patient's management. The MCID is a patient-centered concept, capturing both the magnitude of the improvement and also the value patients place on the change [37,38].

The ability to define a stable, universal MCID score for a particular instrument is an attractive concept for several reasons. Clinically, the MCID score can be utilized to establish a therapeutic threshold via an outcome measure [40].

Though the MCID score is an alluring concept, clinicians must be cautious in accepting an MCID score at face value given the wide variability of established MCID scores available for a single outcome scale. Understanding how these scores were established can facilitate a more nuanced interpretation and application of the MCID score [40].

b) Methods of defining MCID

Two general approaches have been used to determine MCID: anchor-based methods and distribution-based methods. All approaches measure a quantifiable change in outcomes, but the specific choice of approach will decide the type of change measured [39]:

➤ *Anchor-based approaches*

Anchor-based approaches compare the change in patient reported outcomes score to some other measure of change, considered an anchor or external criterion. Very few studies have relied on an objective external criterion [39].

Most commonly, studies compare patient reported outcomes scores to the patients' answers to another subjective assessment, typically a Global Assessment Rating in which the patients rate themselves to some extent as "better," "unchanged," or "worse" [39].

In this first approach, the selection of a group of patients as markers of MCID is arbitrary. The arbitrariness stems from the number of levels in the original scales and from the combination of levels to form the selected patient group [39].

➤ *Distribution-based approaches*

Distribution-based approaches compare the change in patient reported outcomes scores to some measure of variability such as the standard error of measurement (SEM), the standard deviation (SD), the effect size, or the minimum detectable change (MDC) [39].

c) Limitations of MCID determinations

Consensus methods use clinical and domain experts, rather than patients, to define the MCID. In many settings, expert opinion may not be a valid and reliable way to determine what is important to patients [37].

Anchor-based methods are limited by the choice of anchor, which is a subjective assessment. For example, when an anchor is based on asking a patient whether he or she improved after receiving treatment, the response may be susceptible to recall bias. A patient's current status tends to influence recollection of the past. The anchor's validity and reliability are crucial for determination of a valid MCID [37].

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Because distribution-based methods are based on purely statistical reasoning, they can only identify a minimal detectable effect: that is, an effect that is unlikely to be attributable to random measurement error. The lack of an anchor that links the numeric scores to an assessment of what is important to patients causes distribution-based methods to fall short of identifying important, clinically meaningful outcomes for patients. In fact, the term MCID is sometimes replaced by “minimal detectable change” when the difference is calculated by distribution-based methods [37].

Ideally, determination of the MCID should consider different thresholds in different subsets of the population. For example, patients with substantial amounts of pain at baseline might require greater pain reduction to perceive treatment benefit compared with those patients who have little baseline pain [37].

4. Situations where it is indicated to measure QoL.

The question of how frequently, and at what points in time, the quality of life of clinical trial patients should be assessed is closely related to the issue of patient and staff burden. Many clinicians express concern with the burden that quality of life assessments will place on their patients. Although this concern may be justified in some cases, the available evidence suggests that the majority of patients welcome the opportunity to report how their disease and treatment is affecting their daily lives. Nevertheless, an overly frequent data collection schedule will typically result in unacceptable levels of either patient or staff non-compliance [33].

In addition to frequency of administration, the timing of questionnaires can be of critical importance, particularly if one is interested in capturing acute treatment effects. For example, lack of precision in distributing questionnaires intended to be completed by patients at the end of a cycle of chemotherapy may result in serious underreporting of symptoms. In all cases, it can be recommended that quality of life data collection be planned around regularly scheduled medical visits. It is the rare hospital administrator (or patient, for that matter) who would accept additional clinic appointments only for the purpose of such data collection [33].

Its use remains justified in phase III therapeutic trials whose objective is to choose between two treatments. It remains particularly relevant in equivalence trials, where the objective is to choose the therapeutic strategy that will least impair quality of life without loss of efficacy [50]. In these cases, the measurement of quality of life is a secondary endpoint. In contrast, in palliative situations where alternative strategies are evaluated, it is in most cases the primary endpoint.

In clinical research, this type of study provides valid results on average for a given group considered as a reference (target population), and is therefore of collective interest and often delayed (end of study). But sometimes, in certain situations during the development of cancer, such as the end of life, an individual and immediate assessment of the needs and expectations of the patients is preferable, so standard quality of life tools are no longer appropriate [51]. Thus, new tools more specific to these situations, where the patient is his own reference, have been developed. Still few in number today, these are the Schedule for the Evaluation of Individual Quality of Life (SEIQoL) [51] and the Patient-Generated Index (PGI) [52].

Recently, the measurement of quality of life has been raised in clinical practice to assess whether its measurement can improve care. Studies have shown that regular assessment of QoL allows for better doctor/patient communication [53-54-55] and better knowledge of the symptoms and psychosocial problems encountered by patients. However, there are still methodological barriers to its use in current practice.

V. Epidemiology of urothelial cancer

Each year, more than 19 million new cases of cancer are diagnosed worldwide [29]. Globally, one in every five people will develop the disease before the age of 75 years and almost 10 million people die from cancer annually [28].

Based on the latest GLOBOCAN data, bladder cancer accounts for 3% of global cancer diagnoses and is especially prevalent in the developed world. In the United States, bladder cancer is the sixth most incident neoplasm. A total of 90% of bladder cancer diagnoses are made in those 55 years of age and older, and the disease is four times more common in men than women [25].

Bladder cancer also known as urological cancer or urinary bladder cancer, is the 10th most common cancer in the world, and its incidence is steadily on the rise worldwide, especially in developed nations [26,27].

1. Incidence

According to GLOBOCAN [29] data, an estimated 570,000 people were diagnosed with bladder cancer in 2020 as shown in [Figure 24]. This accounts for roughly 3% of all new cancer diagnoses. Nations with the highest rates of bladder cancer are largely found in Asia (36.3%) with the majority of cases in Eastern Asia and Europe (35.6%) with majority of cases concentrated in the Southern and Western parts of the continent, this is showcased in [Figure 25].

The regions with the lowest incidence of bladder cancer include, Central America, the Middle and southern parts of Africa, while the northern parts represent the majority of cases found in Africa. This disparity between continents may be due to the fact that the places with lowest rates of new bladder cancer cases per year are largely composed of nations that are below average on the human development index (HDI), possibly due to lower industrial chemical exposure and limited access to tobacco [26]. In fact, bladder cancer incidence has been found to be positively correlated with HDI and, to a lesser extent, GDP (Gross Domestic Product) per capita [30].

Bladder cancer sits at the 9th position among all cancers in Morocco. According to the national cancer registry of the region of Casablanca, 2.6% of new cancer cases were attributed to bladder cancer, over the period of 2013 to 2017. Men were 5 times more likely to have bladder cancer than women. The incidence of bladder cancer was observed to increase with age, and men over 75 years old represented the majority of registered cases [31].

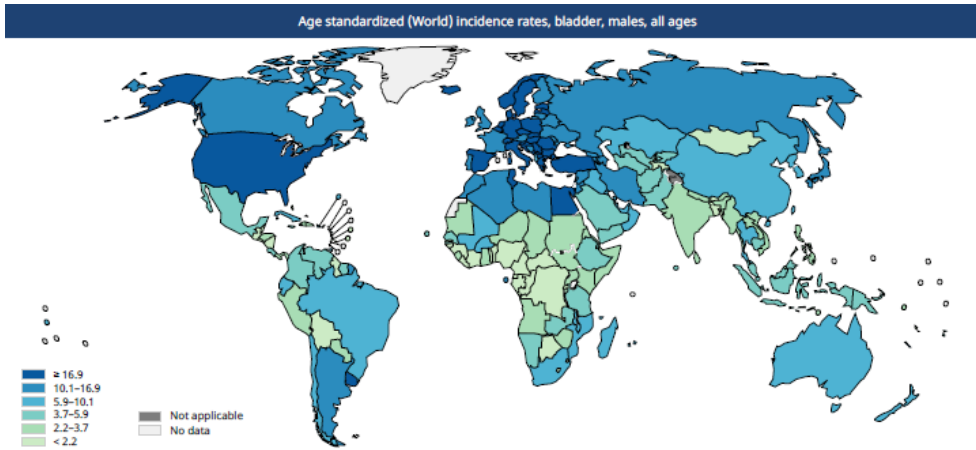


Figure 24: Incidence of bladder cancer in the world 2020 [29].

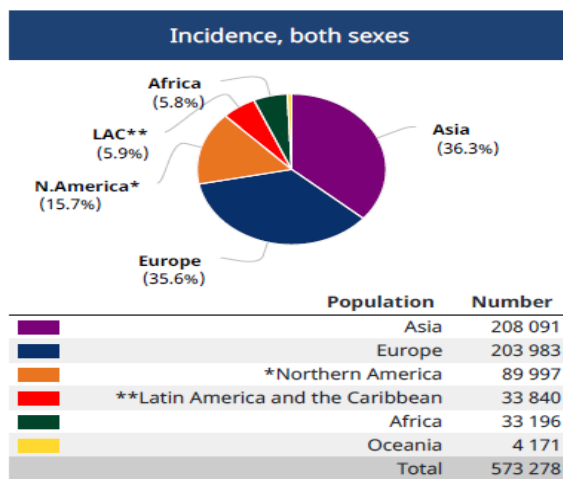


Figure 25: Incidence of bladder cancer by region 2020 [29].

2. Mortality

While bladder cancer is the 10th most common neoplasm throughout the world, it is the 13th most deadly, estimated to have claimed nearly 212,000 lives in 2020 as shown in [Figure26]. This constitutes 2.1% of all cancer deaths [29].

Mortality rates reflect incidence rates in terms of gender disparity, with a mortality of 3.2/100,000 men, which is roughly four times greater than that of women worldwide (0.9/100,000). The cumulative risk of dying from bladder cancer between birth and the age of 74 is 0.29% among men and 0.08% among women. Mortality is greatest in Eastern Asia with china

taking the lead with more than 39000 new death cases in 2020 and Western Europe, this is shown in [Figure 27]. Morocco comes in the 30th place with over 1200 new deaths due to bladder cancer in 2020 [29].

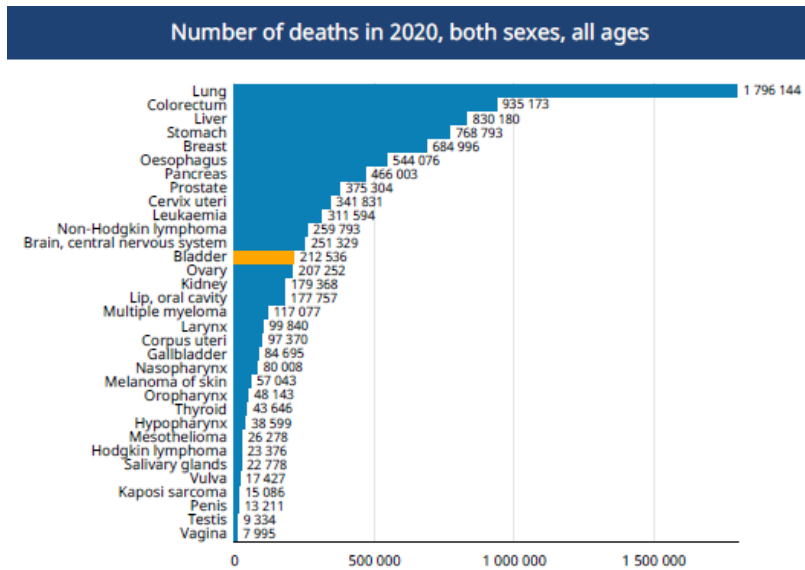


Figure 26: Number of deaths caused by bladder cancer in 2020 [29].

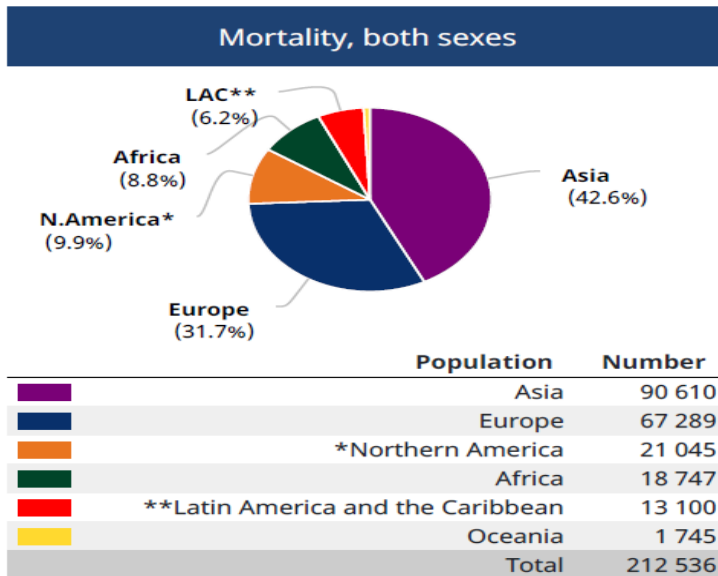


Figure 27: Mortality of bladder cancer by region 2020 [29].

3. Etiology

Urothelial cell bladder cancer accounts for 90% of bladder cancer cases worldwide and is especially common in developed nations.

These cancers migrate beyond the urothelium and invade the submucosa, lamina propria, muscle and serous layers of the bladder. They may also spread directly to adjacent pelvic structures, including the prostate, urethra, uterus, and vagina. Lymphatic metastasis occurs via the obturator, presacral, iliac and para-aortic lymph nodes, while hematogenous spread usually results in metastases to the liver, lungs, bones, and adrenal glands and is associated with a poor prognosis [25].

Five percent of worldwide bladder cancer cases arise from squamous cells, and these cases are more incident in Africa, likely due to schistosomiasis, The remaining 5% are composed of rare subtypes such as adenocarcinoma, sarcoma, and metastases to the bladder [25].

In Morocco ; the most frequent type of bladder cancer is urothelial cell bladder wich accounts for 73.2%, in 10.2% of cases the histological type was unknown [31].

VI. Practical aspects

In our study we conducted a review of litterature on various studies concerning the quality of life in patients with invasive bladder cancer.

All the studies reviewed used the EORTC QLQ-C30 score and the BLM-30 score, this will allow us to compare our results and draw significant observations.

Our review of litterature includes 9 studies as demonstrated in [Table III]. The first one was conducted by Tostivint and al [41] over a period of 7 years and included 73 patients. The second

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study was Cerutto and al [42] over a period of 3 years and included 148 patients. The last was Severin and al [49] over a period of 8 year swich included 61 patients.

The length of the studies included in our review of litterature ranges from 2 years to 8 years with an average of 5.3 years wich is close to our study length of 6 years. Meanwhile the average number of patients included in the different studies was 155 patients, with extremes ranging from 59 patients to 588 patients.

Our study included 15 patients, this difference in number can be explained by the fact that our hospital drains a small geographic area, compared to the centers wich are often multiple hospitals specialized in bladder cancer.

The difference can also be justified by the fact that our study took place amidst the COVID-19 pandemic, wich resulted in a halt in all activities pertaining to the urology departement in favor of it being dedicated to the management of COVID-19 patients.

Table III : Studies included in our review of litterature.

Studies	Country	Number of cases	Length of study
Tostivint and al [41]	France	73 patients	7 years
Cerutto and al [42]	Italy	148 patients	3 years
Arman and al [43]	Armenia	96 patients	2 years
Cathrine and al [44]	Norway	173 patients	6 years
Singer and al [45]	Germany	588 patients	6 years
Sogni and al [46]	Italy	85 patients	4 years
Masson and al [47]	Sweden	59 patients	6 years
Siracusano and al [48]	Italy	112 patients	6 years
Severin and al [49]	Germany	61 patients	8 years
Our study	Morocco	15 patients	6 years

1. Sociodemographic and clinical features

In our series as well as in the other series, the mean age was close with extremes ranging from 57 in the series of Arman and al [43] to 78 in the series of Sogni and al [46] [Table IV].

Table IV : Mean ages of patients across our review of litterature.

Study	Tostivint and al	Cerutto and al	Arman and al	Singer and al	Sogni and al	Siracusano and al	Our study
Age (years)	64	70	57	67	78	71	64.4

In our study, 33% of our patients had some sort of prior medical history, this goes with the statistics of Arman and al [43] study (27.2%) and Cerutto and al [42] (25%). Concurrently, 13% of our patients had significant surgical history, matching with the study of Cerutto and al [42] (25%) [Table V].

Table V : Percentage of patients with medical history across litterature.

Study	Tostivint and al	Cerutto and al	Arman and al	Our study
Medical history	23.6%	25%	27.2%	33%
Surgical history	37%	25%	NA	13%

The tumoral stages of the different patients across the studies were close, with the most frequent stage being T2 with percentage of 66% in our study, 56% in Cerutto and al [42] and 63.3% in Arman and al[43] [TableVI].

Table VI : Tumoral stages of patients across litterature.

Study		Cerutto and al	Arman and al	Siracusano and al	Our study
Tumoral stage	T2	56%	63.3%	30%	66%
	T3-T4	43%	36.4%	35%	34%

In our series 27% of our patients developed post- operative complications, this concures with the data shown in Arman and al [43] study (31.8%) while Cathrine and al [44] study reported (45%) of post-operative complications [Table VII].

Table VII : Post-opreatives of patients across litterature.

Study	Arman and al	Cathrine and al	Our study
Post-opervative complications	31.8%	45%	27%

2. EORTC QLQ-C30 data

In our series as well as in the other series the mean global health score was close with extremes ranging from 57.4 in the series of Severin and al [49] to 79.1 in the series of Mansson and al [47] [Table VIII].

Table VIII : Global health score of patients across litterature.

Study	Cerutto and al	Cathrine and al	Sogni and al	Mansson and al	Siracusano and al	Severin and al	Our study
Global health score	62.33	75.4	65	79.1	62.5	57.4	58

Concerning the functional items of the EORTC QLQ-C30, our results match those of the litterature in terms of physical, emotional, role and cognitive score. On the other hand, our study results fall behind in the social score with an average of 47.3 compared to scores ranging from 71.5 to 85.36.

The physical score refers to the patient's ability to perform daily tasks such as walking, eating and getting dressed. Our results match those of the litterature's as most of our patients have not recalled any serious difficulties tending to their daily tasks, nor did they complain of any restrained mobility nor excessive fatigue.

The role score relates to the patient's capacity in maintaining an active role in everyday life, be that going to work or engaging in hobbies or any other activities. Our patients have reported a moderately high score of role functioning. Most of them did not find any serious hinderances to their daily activities, as they kept having the same hobbies and occupations they had before the surgery. These results match those of the litterature.

The emotional score touches the patient's emotional state after the surgery. It delves into issues such as anxiety, depression and feelings of irritation. The patients in our study scored low compared to those of the other series. We can explain this disparity with the fact that people in Arab and Islamic countries have a high level of stigma and shame surrounding mental illnesses

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such as depression and anxiety. With a lot of people having negative attitudes toward mental disorders and people with mental illnesses. This renders speaking about mental issues taboo and seeking professional help culturally unacceptable which results in the suffering of the patients [91].

The cognitive score refers to the patient's cognitive state including his capacity to concentrate and to remember things. Our results match those of the literature, as our patient reported a high score regarding their cognitive states, with no issues relating to concentration or memory.

The social score pertains to elements of the patient's social activities and interactions. We can explain the disparity between our results and the literature's with the fact that people in Arab countries may attempt to hide their weakness to maintain their traditional role in the community [75], also the fact that a diagnosis of cancer is still mixed with social stigma and misperceptions related to incurability [76].

The table IX, below, summarizes the functional scores of patients across the different studies of the literature.

Table IX : Functional scores of patients across literature.

Study	Cerutto and al	Cathrine and al	Sogni and al	Mansson and al	Siracusano and al	Severin and al	Our study
Physical score	74.73	83.5	78	85.7	73.9	76.58	80.5
Role score	79.61	79.2	83	81.9	78.4	73.68	67.85
Emotional score	78.66	88	87	88.1	80.5	68.88	65.4
Cognitive score	85.36	87.2	90	89.7	87.8	81.95	84.4
Social score	85.36	71.5	83	80.5	84.7	56.73	47.3

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Regarding the symptom items of the EORTC QLQ-C30, our results match those of the literature in terms of the majority of the items from fatigue, nausea and vomiting to constipation and diarrhea [Table X].

Furthermore, our study results are at odds with those of the literature as to financial difficulties with a score of 56.78 versus scores ranging from 6 to 29.07. This indicates that the patients in our series have more financial difficulties than those of the literature.

We can explain the disparity between our results with the fact that all of our patients were retired with nearly half (40%) being financially dependant on others and a third of them were from rural areas.

This mixed with the fact that Moroccan patients, especially those consulting in a public institution, have a low income or are unemployed and do not benefit from social security that covers the majority of medical costs.

The remoteness of patients is also a major contributing factor and imposes expenses for transportation as well as stays during treatment or while waiting for an appointment. All of these factors constitute a major handicap and represent an ineluctable impact on the patient, the health care team and on the treatment [77].

Table X : Symptom scores of patients across litterature.

Study	Cerutto and al	Cathrine and al	Sogni and al	Mansson and al	Siracusano and al	Severin and al	Our study
Fatigue	29.35	25.9	21	22.9	29.1	37.93	21.9
Nausea/ vomiting	4.5	2	2	10.1	5.2	6.54	16.4
Pain	12.27	13.4	4	19	11.8	23.78	14.2
Dyspnea	20.5	23.8	9	15.8	20.5	23.2	23.6
Insomnia	20.05	25	19	1.2	19.3	37.02	30.7
Appetite loss	14.19	6.1	6	2.9	15.2	15.47	16.5
Constipation	31.35	21	33	8.9	33.3	18.17	14.2
Diarhea	8.78	16.7	7	4.7	8.6	15.43	0
Financial difficulties	14.75	9.4	6	7	15.6	29.07	56.78

3. EORTC BLM30 data

As for the items of the EORTC BLM30, our results match those of the litterature in terms of abdominal discomfort and sexual function. On the other hand, our study results are discordant with those of the litterature as to urostomy concerns with a score of 41.5 versus scores ranging from 16.1 to 25.8 ; it was also in disagreement with the future perspective scores. Our series reported a 48.5 score versus scores ranging from 18.3 to 3. Finally, our scores were differed in the body image section with a score of 44.84 versus scores ranging from 20 to 33.3.

In the Moroccan context, the level of study of the patients and illiteracy added to the low income and the poor social security system [77], justifies the high level of concern the patients have about their future be it future treatment plans or future examinations and tests. It also helps explain why patients would find it difficult taking care of their urostomy.

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In addition to this, many patients find it difficult to live and care for their urostomy because of the impact it has on their daily ablutions and prayers. In fact, it is the number one reason for procedure refusal amongst our patients. Prayer is considered one of the five pillars of Islam. Five daily prayers are prescribed and for each, the devotee must hold strict hygiene requirements and be in a state of ritual purity through physical ablution. This state must be maintained throughout the duration of each prayer (5- 10 min) or the prayer is considered invalidated. Bodily functions including voiding and passing flatus or seepage of urine all necessitate repeat ablution. Most fear that continuous expulsion of urine via an ileal conduit will invalidate their ritual purity and as a consequence their acts of prayer. This may be a reason for the significantly lower quality of life reported by Muslim patients following stoma surgery in comparison to non-Muslims. This causes disruption to the religious aspects of the patient's lives, diminishing self-esteem and quality of life [92] [93].

Regarding body image, the high level of concern may be explained by the fact that the physical stigma of cancer exposes a painful and intimate part of a person, which they do not necessarily recognize yet as their own [78], in our case having a urostomy. This part of intimacy, externalized to, can give the feeling of being frozen by the others in an identity which is not their own [78].

Table XI : BLM30 scores of patients across literature.

Study	Tostivint and al	Cathrine and al	Sogni and al	Mansson and al	Siracusano and al	Our study
Urostomy function	25.8	16.1	28	12.7	NA	41.5
Future perspective	27.8	26.1	31	18.3	21.9	48.5
Abdominal discomfort	33.3	14.1	16	24.4	24.7	9.52
Body image	33.3	28.1	20	27.4	29.6	44.84
Sexual function	58.3	NA	NA	44.6	23.3	40.41

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The reported studies in this review were not as helpful as they could have been due to lack of standardisation of outcome definition, collection, and reporting [89].

For urologic surgeons, expertise may influence the choice. However, the current lack of consistency and clarity of what outcomes should be measured and reported seriously hampers decision making by all stakeholders [89].

Hence there is an urgent need to identify a set of core outcomes of universal importance that reflects the perspectives of all stakeholders (patients, urologists, and health care providers). A standardised set of core outcomes will serve as a platform to develop patient reported core outcome measures for use in future studies [89].

It will also facilitate further studies designed to better understand patients' decision-making process, by exploring the weights patients give to alternative outcomes and the trade-offs they make when choosing a particular surgery [89].

By addressing the need for a standardised set of core outcomes and undertaking well-conducted protocol-driven prospective (ideally randomised) multicentre studies the urologic community would stand a better chance of reliably answering these important questions [89].



I. Developpement of awareness campaigns

Clinicians see information from patient-based measures of health as valuable in the overall assessment of the patient and its feedback increases the detection of psychological and, to a lesser extent, functional problems. Indeed, assessments of quality of life may have benefits in daily clinical practice. Used routinely, QoL data can also be useful in monitoring the progression of the disease and the impact of prescribed treatments. In addition, this routine collection of data can improve communication between clinicians and patients, and thus improve patient management [78 ; 79 ; 80].

In order to advance our knowledge of the value of patient-based measures of health in routine practice, there is a need to conduct theory building work to specify what realistic benefits are likely to be gained from their use in routine practice. Studies can then be conducted with explicit hypotheses to assess their effectiveness in this setting [78].

Alongside this, there is a need to design implementation strategies that adequately address the barriers to using patient-based measures of health in routine practice in order to maximize their potential impact.

Independent third-party assessment of QoL should be practised because reports suggest that different results are obtained when a study is administered and analysed by a neutral third party as compared with the surgeon or his or her institution. The authors also found that the results of patient assessed outcomes differ in patients from different sociocultural backgrounds [89].

Finally, there is a need for the reassessment of the aims of health care. The use of patient-based measures of health in routine practice may bring about benefits to patients not traditionally considered to be within the remit of medicine. It is time to question whether the aim of health care really is to improve patient's quality of life as well as address the biological and physiological aspects of disease [78].

A key advancement in the future will be to develop decision aids to help patients make the right choices. These would partly be based on clinical nomograms that can predict cancer

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recurrence and other outcomes for individual patients based on large international databases. It would also ideally include methods to incorporate patients' "cues" or "domains" and concerns important to them.

Individualised QoL interviews such as the SEIQoL-DW can help in the decision-making process. Presurgery, it allows patients to elicit areas or cues that are important in their lives, which can be incorporated in a decision-making tool for the type of transposed intestinal segment surgery offered. Postsurgery, it can help analyse the outcomes and side effects from treatment. To accommodate people with lower literacy, these aids should use common words, short sentences giving examples, or visual aids where applicable [89].

A recent Cochrane review, "Decision Aids for People Facing Health Treatment or Screening Decisions", concluded that patient decision aids increase patients' involvement and hence are more likely to lead to informed values-based decisions [89].

In the long term, such actions could reduce the discrepancies between the patient's declaration of quality of life and the physician's perception of this quality of life, making the use of such a proxy potentially feasible, particularly in the elderly in the general population [79 ; 80].

II. The importance of Cancer Registries in the evaluation of QoL of patients

Although the means and tools that exist today allow us to better prevent and treat cancer, the number of new cases continues to increase. In 2018, the International Agency for Research on Cancer (IARC) estimates the global burden of cancer at 18.1 million new cases and 9.6 million deaths. One in five men and one in six women worldwide will develop cancer and one in eight men and one in 11 women will die from the disease.

The national cancer plan 2020-2029(PNPCC2), defines a number of priorities divided on the four following axis [82] :

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a) Prevention

Prevention remains the most effective way to reduce the incidence and morbidity of cancer.

The PNPCC2 opts to invest heavily in prevention in full coherence with the national multisectoral strategy for the fight against non communicable diseases (NCDs)

The success of this major project depends on the involvement and complementarity between all stakeholders, especially in the fight against environmental risk factors, promotion of a healthy lifestyle, the promotion of physical activity and the surveillance and prevention of risk factors in the in the workplace.

b) Early Detection

The PNPCC2 aims to improve participation in screening and to intensify the fight against inequalities in access to and use of screening, early diagnosis and quality care.

c) Patient management

This 2nd plan proposes to consolidate the achievements, to correct and improve the shortcomings observed, and to support health professionals in the evolution of their of their practice. To allow a complete and innovative care of all cancer patients by motivated and qualified personnel in structures that meet international standards international standards

1. To improve access to early and rapid diagnosis of cancer;
2. To improve access to cancer care and guarantee the quality and safety of treatment;
3. To support health professionals in their practice in the face of scientific, technological and technological and therapeutic developments;
4. To make supportive care an essential lever for the quality of care.

d) Palliative Care

The PNPCC2 advocates the consolidation of achievements and the generalization of palliative care as well as their extension in order to cover the entire national territory.

This care should no longer be the sole responsibility of specialized palliative care teams, except in cases of medium or maximum complexity.

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Because of their comprehensive knowledge of new cases and cancer survivors, cancer registries should play an important role in achieving these goals. The importance of cancer registries lies in the fact that they collect accurate and complete cancer data that can be used for cancer control and epidemiological research, public health program planning, and patient care improvement. Ultimately, all of these activities reduce the burden of cancer [81].

In this context, it may be possible to imagine the establishment, in the future, of a structure inspired by the internet registry PROFILE (Patient Reported Outcomes Following Initial treatment and Long term Evaluation of Survivorship) developed by the Eindhoven Cancer Registry in the Netherlands [83–84]. Such a structure, based on the online collection of quality of life data, would allow the continuous collection of quality of life of cancer patients in order to evaluate the long-term effects of the disease and treatments. It would eventually allow the therapeutic strategy to be adjusted to the needs of patients, in order to add not only years to life, but quality of life to years.

The word "CONCLUSION" is centered on the page, enclosed within a decorative frame. The frame consists of four ornate, black-and-white corner ornaments, each featuring intricate scrollwork and floral patterns. The word "CONCLUSION" is written in a bold, italicized, black serif font.

CONCLUSION

Quality of life among patients after total cystoprostatectomy : perception of moroccan patients.

Bladder cancer is a major global health problem, and its incidence has increased over the past decade. Treatments that have improved patient survival can have physical and psychological repercussions. They can affect their quality of life and make it difficult for them to return to a so-called normal life, especially during the post-treatment phase. Some of these repercussions may persist beyond this period and others may even appear years later.

It therefore seems important to collect long-term information concerning the level of quality of life and reintegration in order to measure the full extent of the impact of the disease and its treatment on patients, their families and society.

Our study joins several studies set up to assess the long-term effects of cancer, and in particular of bladder cancer, on the quality of life and sexuality of patients as well as on their reintegration, especially professionally.

The primary goal of this study was to describe the postoperative quality of life of men who have undergone total cystoprostatectomy as a result of bladder cancer. Its results showed that quality of life after total cystoprostatectomy drops in all spheres of life, including body image, physical health, psychological, social and sexual health. Indeed, patients experience many changes in the pre- and postoperative stages that require adequate medical and nursing intervention.

Finally, this study was also an opportunity to promote reflection about how to extend patients' clinical autonomy [85]. It shines the light on the importance of QoL related issues and their consequences on the daily lives of patients. It also emboldens the impact QoL tools have not only on the patients' management but on their everyday life.



ANNEX 1 :

Operating Form

I- Patient data :

*Name:

1- Age :

3- Marital status : Married Divorced Widowed Single

4-Paternity : Oui Non

5- Socioeconomical level

5-1-Status : Actif Retired

5-2-Financial autonomy : Autonomous Dependent

6-Living area : Urban Rural

8-Social security : yes no

II- Medical History : 1-Personnal :

1-1-Médical : yes type..... no

1-2-Surgical: yes type..... no

2-familial : family history of cancer : yes type..... No

II-Clinical data :

-Date of diagnosis

-Risk factors : tobacco chemical exposure urinary infections treatments(CTH)

-Pathology report

-Post operative complications

Early onset : wound infection sepsis pelvic abcess hemorrhage wound dehiscence bowel obstruction enterocutaneous fistula rectal injury

Late onset : bowel obstruction ureteroenteric stricture renal calculi acute pyelonephritis parastomal hernia stomal stenosis incisional hernia fistula rectal complications

ANNEX 2 :

EORTC QLQ-C30 (version 3)

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

Please fill in your initials:

Your birthdate (Day, Month, Year):

Today's date (Day, Month, Year): 31

Not at A Quite Very All Little a Bit Much

- | | |
|--|---------|
| 1. Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase? | 1 2 3 4 |
| 2. Do you have any trouble taking a long walk? | 1 2 3 4 |
| 3. Do you have any trouble taking a short walk outside of the house? | 1 2 3 4 |
| 4. Do you need to stay in bed or a chair during the day? | 1 2 3 4 |
| 5. Do you need help with eating, dressing, washing yourself or using the toilet ? | 1 2 3 4 |

During the past week: Not at A Quite Very All Little a Bit Much

- | | |
|--|---------|
| 6. Were you limited in doing either your work or other daily activities? | 1 2 3 4 |
| 7. Were you limited in pursuing your hobbies or other leisure time activities? | 1 2 3 4 |
| 8. Were you short of breath? | 1 2 3 4 |
| 9. Have you had pain? | 1 2 3 4 |
| 10. Did you need to rest? | 1 2 3 4 |
| 11. Have you had trouble sleeping? | 1 2 3 4 |
| 12. Have you felt weak? | 1 2 3 4 |
| 13. Have you lacked appetite? | 1 2 3 4 |
| 14. Have you felt nauseated? | 1 2 3 4 |
| 15. Have you vomited? | 1 2 3 4 |
| 16. Have you been constipated? | 1 2 3 4 |

During the past week: Not at A Quite Very All Little a Bit Much

- | | |
|--|---------|
| 17. Have you had diarrhea? | 1 2 3 4 |
| 18. Were you tired? | 1 2 3 4 |
| 19. Did pain interfere with your daily activities? | 1 2 3 4 |
| 20. Have you had difficulty in concentrating on things, like reading a newspaper or watching television? | 1 2 3 4 |
| 21. Did you feel tense? | 1 2 3 4 |
| 22. Did you worry? | 1 2 3 4 |
| 23. Did you feel irritable? | 1 2 3 4 |
| 24. Did you feel depressed? | 1 2 3 4 |
| 25. Have you had difficulty remembering things? | 1 2 3 4 |
| 26. Has your physical condition or medical treatment interfered with your family life? | 1 2 3 4 |
| 27. Has your physical condition or medical treatment interfered with your social activities? | 1 2 3 4 |
| 28. Has your physical condition or medical treatment caused you financial difficulties? | 1 2 3 4 |

For the following questions please circle the number between 1 and 7 that best applies to you

29. How would you rate your overall health during the past week?

1 2 3 4 5 6 7

Very poor

Excellent

30. How would you rate your overall quality of life during the past week?

1 2 3 4 5 6 7

Very poor

Excellent

ANNEX 3 :

EORTC QLQ - BLM30

Patients sometimes report that they have the following symptoms or problems. Please indicate the extent to which you have experienced these symptoms or problems during the past week. Please answer by circling the number that best applies to you.

PLEASE ANSWER QUESTIONS 31 - 37 ONLY IF YOU DO NOT HAVE A UROSTOMY

During the past week: Not A Quite Very at all little a bit much

- | | |
|--|---------|
| 31. Have you had to urinate frequently during the day ? | 1 2 3 4 |
| 32. Have you had to urinate frequently at night ? | 1 2 3 4 |
| 33. When you felt the urge to pass urine, did you have to hurry to get to the toilet? | 1 2 3 4 |
| 34. Was it difficult for you to get enough sleep, because you needed to get up frequently at night to urinate? | 1 2 3 4 |
| 35. Have you had difficulty going out of the house, because you needed to be close to a toilet? | 1 2 3 4 |
| 36. Have you had any unintentional release (leakage) of urine? | 1 2 3 4 |
| 37. Have you had pain or a burning feeling when urinating? | 1 2 3 4 |

PLEASE ANSWER QUESTIONS 38 - 43 ONLY IF YOU HAVE A UROSTOMY

During the past week: Not A Quite Very at all little a bit much

- | | |
|---|---------|
| 38. Has urine leaked from your urostomy bag? | 1 2 3 4 |
| 39. Did you have problems with caring for your urostomy? | 1 2 3 4 |
| 40. Was your skin around the urostomy irritated? | 1 2 3 4 |
| 41. Have you felt embarrassed because of your urostomy? | 1 2 3 4 |
| 42. Have you been dependent on others for caring for your urostomy? | 1 2 3 4 |
| 43. Did you frequently have to change the urostomy bag? | 1 2 3 4 |

PLEASE ANSWER QUESTION 44 ONLY IF YOU HAVE USED A CATHETER DURING THE PAST WEEK

- | | |
|--|---------|
| 44. Have you had problems with self-catheterization? (inserting a tube in the bladder to pass urine) | 1 2 3 4 |
|--|---------|

**During the past week: Not A Quite Very
at all little a bit much**

- | | |
|--|---------|
| 45. Were you worried about your health in the future? | 1 2 3 4 |
| 46. Did you worry about the results of examinations and tests? | 1 2 3 4 |
| 47. Did you worry about possible future treatments? | 1 2 3 4 |
| 48. Have you had a bloated feeling in your abdomen? | 1 2 3 4 |
| 49. Have you had flatulence or gas? | 1 2 3 4 |
| 50. Have you felt physically less attractive as a result of your illness or treatment? | 1 2 3 4 |
| 51. Have you been dissatisfied with your body? | 1 2 3 4 |
| 52. Have you felt less feminine/masculine as a result of your illness or treatment? | 1 2 3 4 |

During the past 4 weeks: Not A Quite Very at all little a bit much

- | | |
|--|---------|
| 53. To what extent were you interested in sex? | 1 2 3 4 |
| 54. To what extent were you sexually active (with or without sexual intercourse)? | 1 2 3 4 |
| 55. For men only: Did you have difficulty gaining or maintaining an erection? | 1 2 3 4 |
| 56. For men only: Did you have ejaculation problems (e.g. dry ejaculation)? | 1 2 3 4 |

**Please answer the following 4 questions only if you have been sexually active during the past 4 weeks:
Not A Quite Very at all little a bit much**

- | | |
|--|---------|
| 57. Have you felt uncomfortable about being sexually intimate? | 1 2 3 4 |
| 58. Have you worried that you may contaminate your partner during sexual contact with the bladder treatment you have been receiving? | 1 2 3 4 |
| 59. To what extent was sex enjoyable for you? | 1 2 3 4 |
| 60. For women only: did you have a dry vagina or other problems during intercourse? | 1 2 3 4 |



Abstract

Our research is a retrospective study involving 15 cases of invasive bladder cancer treated by total cystoprostatectomy in the urology department of Avicenne hospital in Marrakech over a period of 6 years between 2017 to 2022.

The average age was 64.4 years. All our patients were married with 66% living in urban areas. All of them were retired and 40% had no social security coverage.

The analysis of the QLC-C30 score shows a clear deterioration in the quality of life for patients in terms of social and financial difficulties along with an average score pertaining to their global health status. While showing little to no difficulties concerning physical and cognitive functions.

Analysis of the QLQ BLM-30 score shows a deterioration in quality of life in patients, mainly, concerns of future perspective and sexual functions such as erection problems and decrease in libido.

In the light of this study, we have shown that the quality of life of our patients is still distressing in our context compared to developed countries. This can only incite us to make more efforts and to correct the deficiencies found in our management in order to offer a better quality of life to our patients.

Résumé

Notre recherche est une étude rétrospective portant sur 15 cas de cancer invasif de la vessie traités par cystoprostatectomie totale au service d'urologie de l'hôpital Avicenne de Marrakech sur une période de 6 ans entre 2017 et 2022.

L'âge moyen était de 64,4 ans. Tous nos patients étaient mariés et 66% vivaient en milieu urbain. Ils étaient tous retraités et 40% n'avaient pas de couverture sociale.

L'analyse du score QLC-C30 montre une nette détérioration de la qualité de vie des patients en termes de difficultés sociales et financières ainsi qu'un score moyen relatif à leur état de santé global. Tout en montrant peu ou pas de difficultés concernant les fonctions physiques et cognitives.

L'analyse du score QLQ BLM-30 montre une détérioration de la qualité de vie des patients, principalement, des préoccupations concernant les perspectives d'avenir et les fonctions sexuelles telles que les problèmes d'érection et la diminution de la libido.

A la lumière de cette étude, nous avons montré que la qualité de vie de nos patients est encore inquiétante dans notre contexte par rapport aux pays développés. Cela ne peut que nous inciter à faire plus d'efforts et à corriger les déficiences constatées dans notre prise en charge afin d'offrir une meilleure qualité de vie à nos patients.

ملخص

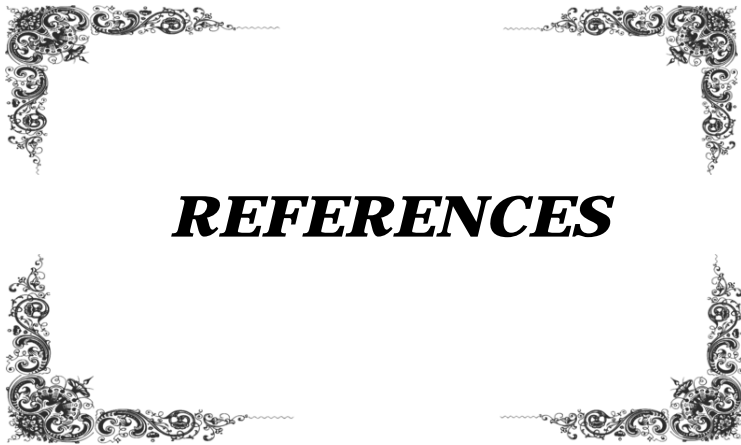
بحثنا عبارة عن دراسة بأثر رجعي لـ 15 حالة من حالات سرطان المثانة التي تم علاجها عن طريق استئصال المثانة والبروستات الكلي في قسم المسالك البولية في مستشفى ابن سينا العسكري في مراكش على مدى 6 سنوات بين 2017 و 2022.

كان متوسط العمر 64.4 سنة. كان جميع مرضانا متزوجين و 66% يعيشون في مناطق حضرية. جميعهم متقاعدون و 40% ليس لديهم غطاء ضمان اجتماعي.

يُظهر تحليل درجة QLC-C30 تدهورًا واضحًا في نوعية حياة المرضى من حيث الصعوبات الاجتماعية والمالية بالإضافة إلى متوسط الدرجة المتعلقة بحالتهم الصحية العامة. بينما تظهر صعوبة قليلة أو معدومة في الوظائف الجسدية والمعرفية.

يُظهر تحليل درجة QLQ BLM-30 تدهورًا في نوعية حياة المرضى ، بشكل أساسي ، المخاوف بشأن الآفاق المستقبلية والوظائف الجنسية مثل مشاكل الانتصاب وانخفاض الرغبة الجنسية.

في ضوء هذه الدراسة ، أظهرنا أن نوعية حياة مرضانا لا تزال مقلقة في سياقنا مقارنة بالدول المتقدمة. يمكن أن يشجعنا هذا فقط على بذل المزيد من الجهود وتصحيح أوجه القصور الملحوظة في رعايتنا من أجل تقديم نوعية حياة أفضل لمرضانا.

The word "REFERENCES" is centered on the page, enclosed within a decorative border. The border consists of four ornate, floral corner ornaments, one in each corner, connected by thin lines. The word "REFERENCES" is written in a bold, italicized, serif font.

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قسم الطبيب

أقسم بالله العظيم

أن أراقب الله في مهنتي و أن أصون حياة الناس في كافة أدوارها في كل الظروف و الأحوال باذلتنا وسعي في استنقاذها من الهلاك والمرض والألم و القلق

و أن أحفظ للناس كرامتهم و أستتر عورتهم و أكتم سرهم و أن أكون على الدوام من وسائل رحمة الله، باذلتنا رعايتي الطبية للقريب و البعيد، للصالح و الطالح، و الصديق و العدو.

و أن أثابر على طلب العلم، أسخره لنفع الناس لا لأذاه و أن أوقر من علمني، و أعلم من يصغرنني، و أن أكون أختا لكل زميل في المهنة الطبية متعاونين على البر و التقوى و أن تكون حياتي مصداق إيماني في سري و علانيتي، نقية مما يشينها تجاه الله و رسوله و المؤمنين و الله على ما أقول شهيد





كلية الطب
والصيدلة - مراكش
FACULTÉ DE MÉDECINE
ET DE PHARMACIE - MARRAKECH

أطروحة رقم 312

سنة 2022

جودة حياة المرضى بعد استئصال المثانة والبروستاتا: تجربة المرضى

بالمغرب.

الأطروحة

قدمت و نوقشت علانية يوم 2022/11/22

من طرف

السيدة ريم المكوسي

المزداة في 16 ماي 1997 بمراكش

لنيل شهادة الدكتوراه في الطب

الكلمات الأساسية:

جودة الحياة-سرطان المثانة- اختبار EORTC QLQ C30/BLM30

اللجنة

الرئيس	م. الزياتي	السيد
	أستاذ في الطب الباطني	
المشرف	ع. غوندال	السيد
	أستاذ في جراحة المسالك البولية	
الحكم	م. أفينتي	السيد
	أستاذ في طب النفس	