Bladder cancer treatment decision, management, and psychosocial outcomes: Results of patients’ interviews

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What are the implications of bladder cancer treatment’s outcomes for:

- BLCA patients?
- Health care providers?
- Research?
Bladder cancer

- 5th most common cancer, and the most common type of urinary tract cancers.
- > 68,810 new cases of bladder cancer and about 14,000 deaths in 2009.
- ≈80% of new cases occur in men and ≈ 20% in women
- 90% of patients are over the age of 55
- 2 times greater in whites compared to blacks

American Cancer Society. Cancer facts and figures 20069 graphs and figures.
http://www.cancer.org/docroot/MED/content/MED_1_1_Most-Requested_Graphs_and_Figures_2009.asp.
Prevalence

American Cancer Society. Cancer facts and figures 2006 graphs and figures. 
http://www.cancer.org/docroot/MED/content/MED_1_1_Most-Requested_Graphs_and_Figures_2006.asp
Invasive Bladder cancer

Of the 68,810 newly diagnosed patients ≈ 30% have muscle invasive bladder (stage T2-T3b)

• Removal of the bladder (Radical Cystectomy)

Tis: carcinoma in situ
Ta: noninvasive papillary carcinoma
T1: invasion of subepithelial connective tissue
T2: invasion of muscle layer
T3: invasion of perivesical tissue
T4: invasion of nearby organs
Invasive Bladder Cancer Treatment

Radical Cystectomy:

- Removal of the bladder in men routinely include removal of:
  - the prostate
  - seminal vesicles
- Removal of the bladder in women routinely include removal of:
  - the uterus
  - fallopian tubes
  - Ovaries
  - cervix
Urinary Diversion

➢ Creation of an artificial bladder

**Aim**: Replace the function of native bladder with a urinary diversion form to:

- store urine without absorption of the waste products,
- store urine at low pressure so that the urine can continue to drain from the kidneys,
- prevent reflux of urine back to the kidneys, and
- empty completely.

- Urinary diversion form should be emotionally and socially-acceptable.

*So Far, there is no perfect form of urinary diversion!!!*
Types of Urinary Diversion

Ileal Conduit (incontinent diversion to skin)

Continent Cutaneous Reservoir (continent diversion to skin)

Orthotopic Neobladder (continent diversion to urethra)

**SIMILAR** rates of cancer control and recurrence-free survival (87% - 76% in 5-10-year)

Figures from [www.clevelandclinic.org/health/health-info/docs](http://www.clevelandclinic.org/health/health-info/docs); Raj, GV, Bochner B. Radical cystectomy and lymphadenectomy for invasive bladder cancer: Towards the evolution of an optimal surgical standard" Seminars in Oncology, In press.
Ileal Conduit (IC)

Pros

• Simple to perform
• Least potential for post-treatment complications
• No need for catheterization
• Less absorption of urine

Cons

• Need to wear an external collection bag
• Stoma complications (e.g., hernia)
• Long-term sequelae (e.g., renal deterioration)

Continent Cutaneous Reservoir (CCR)

**Pros**

- No external bag
- Stoma can be covered with bandaid

**Cons**

- More complex than IC
- Need for regular catheterization (4 times/day)
- Potential complications (e.g., infection)
- More absorption of urine

Orthotopic Neobladder

**Pros**

- No external bag or stoma
- Urinate through urethra
- May not need catheterization

**Cons**

- Incontinence (10-30%)
- Urine retention (5-20%)
- Potential complications (e.g., infection)
- Need to “train” neobladder & learn how to catheterize

Urinary Diversion: Research Outcomes

4 recent reviews of the literature:

✅ No published studies on patients’ informational needs

✅ No published studies on Bl Ca treatment decision making

✅ Only 33 articles on HRQOL

✅ No single randomized study was conducted to examine QOL among bladder cancer patients

✅ Only 4 studies prospectively examined QOL and adjustment among this population

Urinary Diversion: Research Outcomes

Aim: Examined quality of life and Adjustment after treatment

Participants: Patients with Ileal conduit (n = 20) and continent reservoir (n = 24).

Design & Measures: SF-36; EORTC-QLC-C30; FACT-G. After diagnosis and at 2-W, 3-W, and 1 year following cystectomy

Results:

1) Significant decline in physical & emotional QOL and role functioning compared to general population regardless of treatment received.

2) Higher levels of perceived global satisfaction regardless of the treatment received.

Urinary Diversion: Research Outcomes

Other research findings:

Compared to continent reservoir and neobladder patients, Ileal Conduit patients are more likely to report:

- uneasiness due to fear of urine leakage,
- bother with odor,
- impaired body image, and
- Sexual dysfunction, and are less likely to report
- frequent leisure activities and travel.

**Urinary Diversion: Research Outcomes**

**Daytime Urinary Leakage**
- Over the past 4 weeks, how often have you leaked urine while awake and doing your routine activities:
  - No at all
  - Less than once a week
  - About once a day
  - Every day

**Daytime Urinary Control**
- Over the past 4 weeks, which of the following best describe your urinary control when you are awake:
  - Total control
  - Occasional dribbling
  - Frequent dribbling
  - No control whatsoever

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Urinary Diversion: Research Outcomes

**Nighttime Urinary Leakage**
- Over the past 4 weeks, how often have you leaked urine while sleeping:
  - no at all
  - less than once a week
  - about once a day
  - every day

**Nighttime Urinary Control**
- Over the past 4 weeks, which of the following best describe your urinary control when you are sleeping:
  - total control
  - occasional dribbling
  - frequent dribbling
  - no control whatsoever

Urinary Diversion: Research Outcomes

Invasive Bl Ca treatment options have:

1. **SIMILAR** rates of cancer control and recurrence-free survival (87% - 76% in 5-10-year)

2. **DIFFERENT** effects on:
   - quality of life
   - body-image
   - post-treatment health care

Study Questions

What are the implications of bladder cancer treatment outcomes for:

- BL CA patients?
- 1. SIMILAR survival rates
- 2. DIFFERENT side effects
- Research?
- Health care providers?
What do bladder cancer patients need to know about bladder cancer?

Implications for BL Ca patients?

1. SIMILAR survival rates
2. DIFFERENT side effects

Actually
Implications for BL Ca patients

**Aim:** To examines patients’ informational need

**Participants:** Bl Ca patients ($n_{men} = 3; n_{women} = 5$)

Age: $M = 61.5$ Yrs

Time since treatment: $M = 2$ years and 5 months

Treatment: Ileal Conduit ($n = 3; 37.5\%$)
  - Continent reservoir ($n = 1; 12.5\%$)
  - Neobladder ($n = 4; 50\%$)

**Method:** Patients’ interviews:
1. Patients’ information seeking & understanding of BL Ca
2. Treatment decision making & patients’ roles
3. Treatment and side effect
4. Health care following treatment
Patients’ information seeking & understanding of BL Ca

- Did not have enough information about BL Ca treatment: 100%
- Physician recommended BL Ca treatment: 62%
- Searched internet for information about BL Ca and treatment: 38%
- Asked another patient about BL Ca and treatment: 25%
BI Ca treatment decision making and Patients’ role in decision making

- Followed physician’s recommendation: 50%
- Physician discussed only one treatment: 13%
- Physician discussed > 1 treatment: 87%
- Physician discussed pros and cons of > 1 treatment: 38%
Bl Ca treatment decision making and Patients’ values clarifications

- “As soon as my Dr talked about the neo-bladder I said “that it” because it was the most natural thing. I just knew I didn’t want a bag and I didn’t want to have to catheterize myself.”  A patient with neobladder

- “I decided to have the ileal conduit although I was not totally understanding of what a stoma was, and how it worked, and how the attachment worked. That was never really clear to me”. A patient with ileal conduit
Bi Ca treatment decision making and Patients’ values clarifications

Quality Decision Making:

• Full information about treatment and benefits and risks
• Realistic personal expectation of treatment
• Treatment decisions should reflect patient’s values and goals

• Decisional regret, and dissatisfaction with treatment and health care.

BI Ca treatment decision making and Patients’ values clarifications

- “I’m not too much happy, but what are you gonna do? I can do nothing. I thank god I’m still here. That’s it.”
  A patient with ileal conduit

- “Sometimes when you’re older I don’t know if you can handle something like this….I don’t recommend this treatment for older people who can not take care of themselves”. A patient with continent reservoir
Lack of knowledge about post-treatment care and consequences

Did not know what to expect after surgery: 100%
Did not know how to use catheters: 100%
Difficulty using stoma appliances: 100%
Lack of knowledge about post-treatment care and consequences

“Before I was discharged, the ostomy nurse came in and she put the bag, this and that, she showed me—I’ve never seen anything like that in my life...............By the time I got home, the bag almost exploded. I didn’t know what to do. They never prepared me for what could happen. I got home and ...I had no idea.....The bag came off. I was in the bathroom, standing in the tub with urine running down my body,... crying”. A patient with ileal conduit
Study Questions

What are the implications of bladder cancer treatment’s outcomes for:

1. SIMILAR survival rates
2. DIFFERENT side effects

BLCA patients?

Health care providers?

Research?
Implications of BL Ca treatment outcomes for patients: Patients need to:

- have full information about Bl Ca treatment and side effects
- be actively involved in treatment decision making
- have access to decisional aid that provide value clarification exercises
- receive training on patient-physician communication skills
- receive training on health care following treatment
**Implications of BL Ca treatment outcomes for research:** Research should expand from the existing QOL issues to:

- Focus on decisional support issues
- Examine influence of decisional regret and conflict on QOL
- Bring effective components into assessment of QOL (e.g., body image, gender and age differences in body image and QOL)
- Apply educational and psycho-social interventions to improve QOL and post-treatment health care
- Improve research method & design (e.g., prospective, longitudinal studies.)
Implications of BL Ca treatment outcomes for providers: Health care providers should improve and standardize BL Ca health care by providing:

- Educational materials before and after treatment
- Consultations with stoma nurses to discuss treatment options, side effects, clarify values, and address concerns before and after treatment
- Increase number of home visits for post-treatment health care training
Thank you for your attention

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Summary: BL Ca research limitations

• No published studies on Bl Ca patients’ informational needs
• No published studies on Bl Ca treatment decision making
• Few published studies on QOL after Bl Ca

“Bl Ca research lags significantly behind that of other cancers both in terms of adequacy of HRQOL instruments and breadth and depth of published studies”. (Latini et al., Urology, 2010, 334-339)
Risk Factors for Bladder Cancer

- Age (risk increases with age)
- Race (incidence is 2 times greater in whites compared to African-Americans)
- Gender (incidence is 4 times greater in men)

- Exposure to cigarette smoke
- History of external beam radiation
- Neurogenic bladder, recurrent urinary tract infections, urinary stones, chronic indwelling catheter

- Infection with *Schistosoma haematobium*
- Ingestion of *Aristolochia fangchi* (herb used in some weight-loss formulas)

- Exposure to chemicals (hair dyes, aniline, organic solvents, etc)
- Exposure to arsenic
- Personal or family history of bladder cancer
What do cancer patients need to know?

- Descriptions of cancer progression
- Likelihood of cure and control
- Treatment choices
- Short- and long-term treatment side effects
- Benefits and risks of different treatment options
- Future-oriented information to prepare for the unknown:
  - Adjustment to medical environment & procedures
  - Preparing for follow-up and screening tests

What do bladder cancer patients need to know about bladder cancer?
Bladder cancer

• Bladder cancer: Incidence, mortality, & risk
• Treatment options & side effects
• Previous research focus & outcomes
• What should patients know about Bl Ca?
• Results of patients’ interviews
• Implications for patients, research, & health care providers