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INFORMATION AND SUPPORTIVE CARE NEEDS OF INDIVIDUALS WITH BLADDER CANCER

ROBIN MORASH
APN, URO-ONCOLOGY

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The Ottawa
Hospital | L'Hôpital
d'Ottawa

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PRESENTATION CONTENT

- ▶ Overview of bladder cancer
- ▶ Study purpose
- ▶ Methodology and results
- ▶ Conclusions
- ▶ Implications for nursing practice

PRESENTATION OUTCOMES

FOLLOWING THE PRESENTATION ATTENDEES WILL BE ABLE TO:

- ▶ Describe the trajectory of bladder cancer care
- ▶ Understand the rationale for the study
- ▶ Describe study results and implications
- ▶ Adopt learnings into practice



ACKNOWLEDGEMENTS

- ▶ Conflicts of Interest: None
- ▶ Study team:
 - Jiil Chung, Girish Kulkarni, Robin Morash, Andrew Matthew, Janet Papadakos, Rodney Breau, David Guttman, Jackie Bender, Jennifer Jones

BLADDER CANCER OVERVIEW



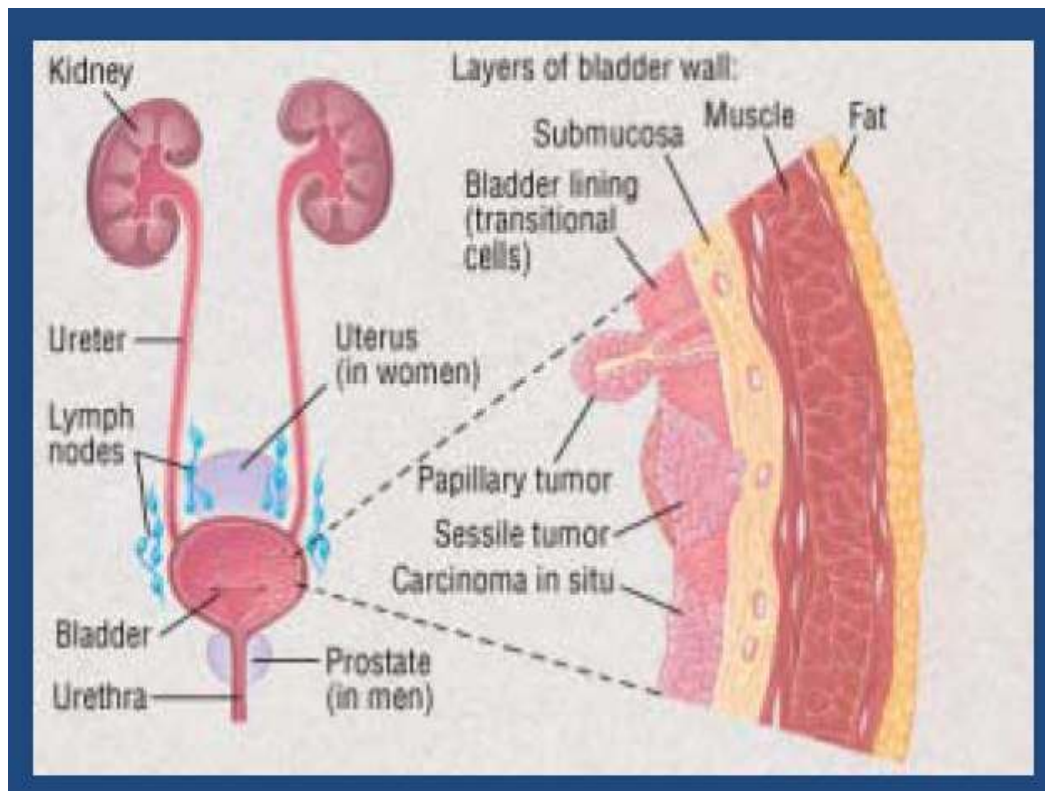
STATISTICS

- ▶ 5th most common cancer in Canada
- ▶ 8900 Canadians newly diagnosed (CCS 2017)
 - 80% bladder cancer (NMIBC)
 - 20% muscle invasive bladder cancer (MIBC)
- ▶ 2400 Canadians will die of bladder cancer/year

BLADDER CANCER – RISK FACTORS

- ▶ More common men and >70 years of age
- ▶ Smoking is most common risk factor
- ▶ Occupational exposure to certain industrial chemicals
- ▶ Cancer treatments – radiation, cyclophosphamide
- ▶ Chronic bladder inflammation
- ▶ Personal or family history of bladder cancer

BLADDER CANCER - STAGES



1. NMIBC TUMOURS AT RISK OF RECURRENCE

- ▶ Low grade, non-invasive, multiple tumours
- ▶ Require repeated scrapings –TURBT
- ▶ Only 1-3% progress to riskier form
- ▶ Sometimes use Mitomycin-C to prevent recurrences
- ▶ Regular cystoscopy to monitor for recurrences.

2. NMIBC TUMOURS AT RISK OF PROGRESSION

- ▶ High grade, CIS, T1(through top layer)
- ▶ 10-50% will become muscle invasive
- ▶ Treat with immunotherapy – BCG
- ▶ Reduces progression rates
- ▶ If no response can try BCG with Interferon
- ▶ If progress to muscle invasive then need to consider bladder removal, +/- chemo, radiation

3. LOCALIZED MUSCLE INVASIVE BLADDER CANCER

Treatment Options

Surgery

+/- neoadjuvant chemotherapy
+/- adjuvant chemotherapy

Radiation (bladder sparing)

+/- chemotherapy

LOCALIZED MUSCLE INVASIVE BLADDER CANCER

Without chemotherapy



With chemotherapy



MIBC - URINARY DIVERSION OPTIONS

Urinary Diversions:

1. Ileal Conduit (1950's)
2. Continent reservoir pouch (1980's)
3. Neobladder (1980's)

Choice depends on:

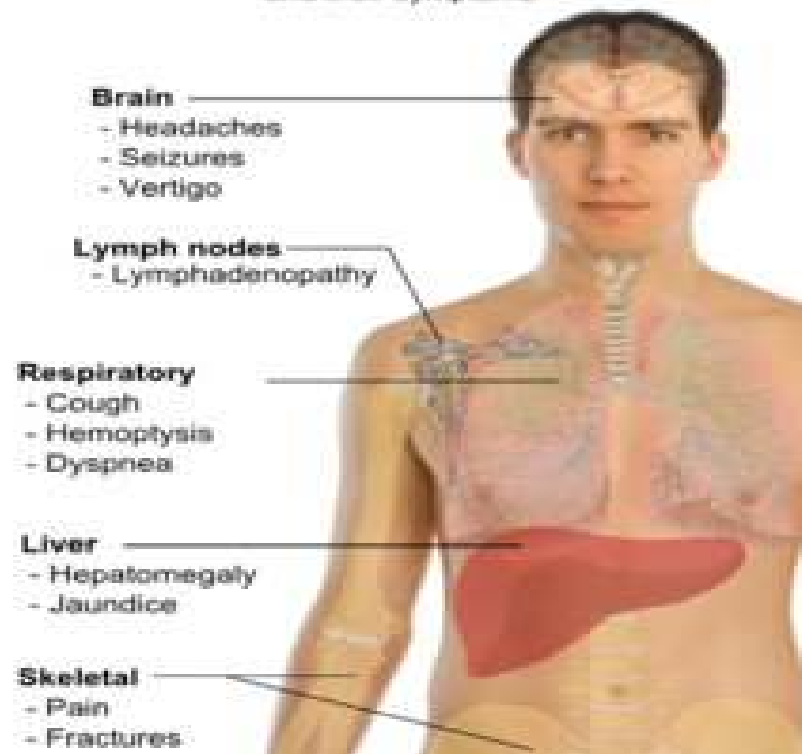
- o Size, location of tumour
- o Stage
- o Age, fitness of patient, other health problems
- o Patient preference

4. METASTATIC/ADVANCED BLADDER CANCER

- ▶ Some patients will develop metastatic disease.
- ▶ No longer curable but treatable
 - Life expectancy on average approx. 14 months
- ▶ Common sites of metastasis
 - lungs, liver, bone, brain, lymph nodes
- ▶ Chemotherapy, radiation, surgery- can all improve quality of life
- ▶ Supportive Care:
 - Pain medications, Oxygen

METASTATIC BLADDER CANCER

Most common sites of
Cancer metastasis
and their symptoms



STUDY PURPOSE

- ▶ Sparse research on QoL, informational, supportive care needs
- ▶ Dearth of resources available
- ▶ Objective:
 - Assess and describe the informational and supportive care (I+S) needs of people who have been diagnosed with bladder cancer

METHODS

- ▶ Cross-sectional self-report survey
 - Assessing QoL – BUSS tool – domains: medical, physical, practical, emotional, social and spiritual
 - I+S care needs – CaSUN measure – 35 items in 5 domains: information, comprehensive cancer care, existential survivorship, QoL, and relationships
- ▶ Participants recruited from:
 - Bladder Cancer Canada
 - Princess Margaret Hospital
 - The Ottawa Hospital
- ▶ Data collection: March 2014-April 2016

RESULTS

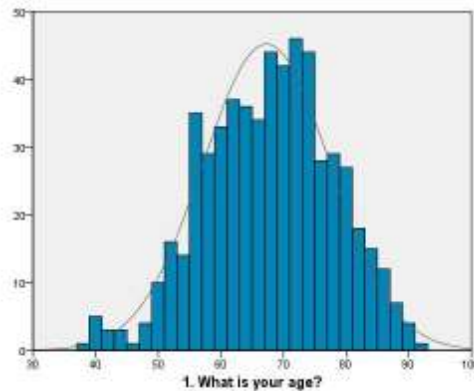
- All results were provided in total scores and also by recruitment sites:
 - BCC
 - PMH
 - TOH

- ▶ Demographics
 - Age
 - Gender
 - Education level
 - Country of birth
 - Used internet resources for learning about BC
 - Accessed BCC website
- ▶ Clinical
 - Timeframe of diagnosis (from study date)
 - Type of BC, TNM staging
 - Treatment types
 - Cancer journey stage
 - BMI, smoking behaviours, ETOH, exercise

RESULTS – DEMOGRAPHICS

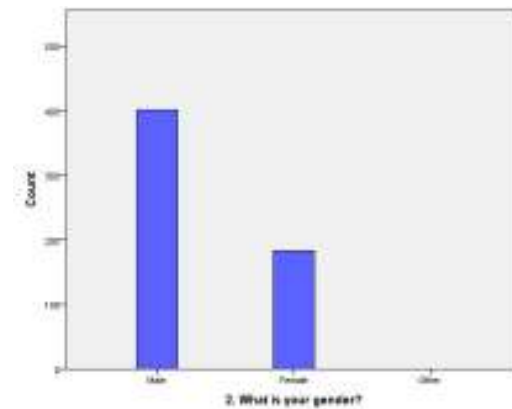
N=586

Cohort age



Mean = 67.29
Median = 68.00
Min = 38, Max = 92

Cohort gender



Male = 69% (401)
Female = 31% (183)
Total = 584

RESULTS – CLINICAL - 1

| Cancer type | % of respondents |
|-------------|------------------|
| NMIBC | 58% |
| MIBC | 23% |
| Didn't know | 18% |

| Time of dx | % of respondents |
|---------------|------------------|
| 0-2 years ago | 13% |
| 2-5 years ago | 50% |
| 5+ years ago | 32% |

| Cancer trajectory | % of respondents |
|--------------------------------------|------------------|
| Newly diagnosed, receiving treatment | 13% |
| Post treatment, f/u care | 66% |
| Metastatic/recurrent | 15% |

RESULTS

QUALITY OF LIFE

Findings not unexpected:

- ▶ Respondents with MIBC had significantly lower quality of life scores than those with NMIBC
- ▶ Quality of life scores differed across cancer trajectory groups:
 - The follow-up surveillance group reported significantly higher QoL compared to newly diagnosed and metastatic/recurrent groups
 - The metastatic/recurrent group has significantly lower overall health scores compared to those in follow-up/surveillance

RESULTS

INFORMATION NEEDS

- ▶ % items rated important varied across domains: medical, physical, practical, emotional, social and spiritual
- ▶ 10 most highly ranked were from medical (5), physical (3), and practical domains (2)
- ▶ MIBC and NMIBC groups had similar info needs except:
 - NMIBC had higher practical needs
- ▶ Needs were same in all 3 trajectory groups with one exception

The 10 most important informational needs

| Informational Needs | % of participants who found the item important or very important | Domain |
|---|--|-----------|
| 1. General information about cancer | 88% | Medical |
| 2. Possible side effects of treatment | 88% | Medical |
| 3. How to manage side effects of treatment | 88% | Medical |
| 4. Treatments advantages/disadvantage | 86% | Medical |
| 5. Which symptoms to monitor and report in the future | 86% | Physical |
| 6. Further medical tests after treatment | 84% | Medical |
| 7. How often to visit the doctor | 82% | Practical |
| 8. Drug coverage options | 75% | Practical |
| 9. Expected pace of recovery | 72% | Physical |
| 10. How to manage changes to memory and attention | 70% | Physical |

RESULTS

SUPPORTIVE CARE NEEDS

- ▶ Items examined to ID if needs present and unmet
- ▶ 35 items in 5 domains: information, comprehensive cancer care, existential survivorship, QoL, and relationships
- ▶ 14% reported “not needed or n/a” for all 35 needs
- ▶ Most common needs were ID'd in comprehensive cancer care domain (82%) followed in order by:
 - Existential survivorship (65%)
 - Information (55%)
 - QoL (47%)
 - Relationship (35%)

The 10 most commonly endorsed supportive care needs (met or unmet) in the CaSUN

| Item | % endorsing |
|---|-------------|
| 1. The very best medical care | 68% |
| 2. To feel like I am managing my health together with the medical team | 68% |
| 3. Concerns regarding my care to be properly addressed. | 67% |
| 4. To know that all my doctors talk to each other to coordinate my care | 64% |
| 5. Information provided in a way that I can understand | 52% |
| 6. Local healthcare services | 50% |
| 7. Help to manage my concerns about the cancer coming back | 47% |
| 8. Up-to-date information | 46% |
| 9. Help to manage ongoing symptoms and side effects | 44% |
| 10. Emotional support | 39% |

RESULTS

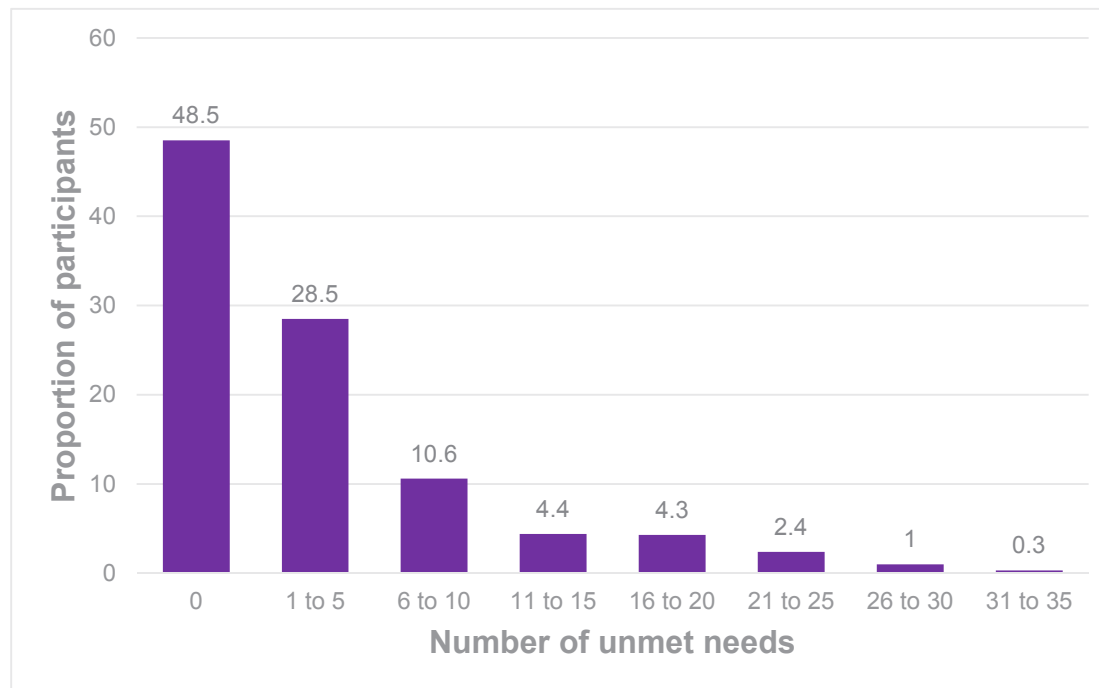
SUPPORTIVE CARE NEEDS - 2

- ▶ Just over half (54%) – at least 1 unmet need
- ▶ 15% reported ≥ 10 unmet needs
- ▶ Mean # of unmet needs was 4.2(+/-6.7)
- ▶ MIBC had av. of 4.6 unmet needs, NMIBC 4.2
- ▶ Unmet needs by trajectory:
 - Newly dx'd/treatment had average of 7.4
 - post treatment/follow up (3.6)
 - metastatic/recurrent (4.6)
- ▶ Lower age, newly dx'd/treatment, lower BUSS (QoL): all associated with higher total unmet needs
- ▶ No difference: based on sex, education, geography, type of bladder cancer

The 10 most commonly unmet supportive care needs in the CaSUN

| Item | % endorsing as unmet |
|--|----------------------|
| 1. Help to address problems with my/our sex life | 76% |
| 2. Help to try to make decisions about my life in the context of uncertainty | 71% |
| 3. Help to cope with others not acknowledging the impact that cancer has had on my life | 69% |
| 4. Help to cope with expectations of me as a cancer survivor | 67% |
| 5. Help to cope with changes to my belief that nothing bad will ever happen in my life. | 64% |
| 6. Help developing new relationships after the cancer. | 62% |
| 7. Help to find out about financial support or governmental benefits to which I am entitled. | 60% |
| 8. More accessible hospital parking | 60% |
| 9. Help to deal with the impact that cancer has had on my relationship with my partner | 59% |
| 10. Help getting life and/or travel insurance. | 59% |

Proportion of participants reporting unmet needs



DISCUSSION

- Information needs

- ▶ All domains of information rated very high with basic information on bladder cancer, treatments and treatment side effects along with the management of physical side-effects as most important.
- ▶ High ranking of medical, physical and practical domains suggest nature of these needs may cross the cancer phases
- ▶ 18% did not know what type of bladder cancer they had been diagnosed with.
- ▶ Health care professionals play an important role in patient education at all phases of the disease
- ▶ Need consistent patient educational resources and a standardized approach to the embed information within treatment pathways

DISCUSSION

- Supportive care needs

- ▶ 86% of respondents indicated > 1 supportive care need
- ▶ 54% reported >/= unmet needs -coping and adjustment; relationship and practical needs
- ▶ Most common needs centered around the provision of care
- ▶ Total number of unmet needs was statistically significantly related to quality of life
- ▶ Existential domain had the most frequently unmet needs, 1/3 of respondents (38%) indicating at least one unmet need in this domain. These items mirror other disease sites:
 - fear of recurrence, reducing stress, coping with others' expectations as a cancer survivor, and other psychological needs.
- ▶ Newly diagnosed had a significantly higher number of unmet

LIMITATIONS

- ▶ The findings of this study need to be interpreted considering its limitations:
- ▶ Cross-sectional study providing a single snapshot and does not allow for the examination of cause and effect relationships.
- ▶ Restricted to English-speaking residents in Canada
- ▶ May not be representative of non-English speaking individuals or those outside of Canada.

CONCLUSIONS

- ▶ Treatment for bladder cancer complex, high rate of recurrence MIBC
- ▶ Multiple treatment modalities, learning needs
- ▶ Difficult treatment decisions
- ▶ Despite identified initial and ongoing support, very little resources for patients with bladder cancer
- ▶ Study provides initial groundwork to improve care across trajectory
- ▶ Need to develop and tailor programs to meet specific needs of patients
- ▶ Next steps – review areas for development
- ▶ -recommend same type of study for caregivers

IMPLICATIONS FOR NURSING

- ▶ Understand complexity of disease: types, treatments, potential outcomes
- ▶ Develop skill in decision counselling
- ▶ Ongoing assessment of patient's information and supportive care needs
- ▶ Providing connections: patients appreciate talking to someone who has been through the treatment they are considering
- ▶ Be aware of and provide connection to local or national resources:
 - Bladder Cancer Canada, local support groups
 - Bladder Cancer Advocacy Network (US)
 - Ostomy Associations in local area

THANK YOU!