

Symptoms, health-related quality of life, and burden among patients with high-risk non-muscle invasive bladder cancer and caregivers

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Conclusions

Patients with HR-NMIBC report significant impairment to their role functioning and work/daily activities, their caregivers are also impacted

– Patients experienced more symptoms, both at diagnosis and at data collection, than what physicians reported on their behalf

Our findings highlight the importance of collecting data from patients and caregivers, in addition to physicians, to fully understand the burden of HR-NMIBC

Treatment burden was evident in the majority of patients with HR-NMIBC globally, with over half of patients unsatisfied with their overall treatment for HR-NMIBC

Caregivers of patients with HR-NMIBC reported impact to their daily activities and finances

Our results underscore the unmet need for treatment options for HR-NMIBC that minimize burden on patients and their caregivers

Background

- Non-muscle-invasive bladder cancer (NMIBC) accounts for approximately 75% of all bladder cancers, and patients with high-risk (HR) NMIBC are at increased risk for recurrence and progression to muscle-invasive bladder cancer^{1,2}
- The existing standard of care for HR-NMIBC, such as BCG and other intravesical treatments, may be burdensome to patients and their caregivers, with considerable local and systemic side effects³
- However, data on health-related quality of life (HRQoL) and symptoms of patients with HR-NMIBC and caregiver impact are limited
- Comprehensive global understanding of patient symptom burden, HRQoL, and treatment satisfaction along with caregiver burden is needed

Objectives

To evaluate patient HRQoL in HR-NMIBC, patient vs physician-reported symptoms, and caregiver burden from patients, physicians, and their caregivers

Results

- 774 patients, 175 physicians, and 397 caregivers participated in the survey
- Patients on average were 2.1 years post-HR-NMIBC diagnosis
- Baseline patient demographic and clinical characteristics were similar across regions
- The majority of treating physicians were oncologists (59%) in Europe and were urologists (88%) in Asia
- Of the caregivers surveyed,
 - Three quarters lived with the patients
 - The majority were spouses or partners

Table 1: Baseline sociodemographic and clinical characteristics

| Patient characteristics | Overall (N=774) | Asia Pacific (n=301) | Europe (n=473) |
|---|-----------------|----------------------|----------------|
| Age, years, mean (SD) | 66.6 (9.8) | 62.0 (10.6) | 69.5 (7.9) |
| Male, n (%) | 614 (79) | 240 (80) | 374 (79) |
| ECOG at diagnosis, n (%) | | | |
| 0 | 275 (36) | 107 (36) | 168 (36) |
| 1 | 415 (54) | 174 (58) | 241 (51) |
| 2 | 75 (10) | 17 (6) | 58 (12) |
| 3 | 6 (1) | 3 (1) | 3 (1) |
| Don't know | 3 (<1) | 0 (0) | 3 (<1) |
| Tumour stage at time of data collection, n (%) | | | |
| CIS only | 97 (13) | 20 (7) | 77 (16) |
| CIS+Papillary | 58 (7) | 25 (8) | 33 (7) |
| Papillary only | 619 (80) | 256 (85) | 363 (77) |
| Receiving treatment at time of data collection, n (%) | | | |
| Yes | 272 (35) | 75 (25) | 197 (42) |
| No | 382 (49) | 193 (64) | 189 (40) |
| Unknown | 120 (16) | 33 (11) | 87 (18) |
| Physician characteristics | Overall (N=175) | Asia Pacific (n=57) | Europe (n=118) |
| Primary speciality, n (%) | | | |
| Medical oncologist | 313 (40) | 35 (12) | 278 (59) |
| Urologist | 461 (60) | 266 (88) | 195 (41) |
| Practice setting, n (%) | | | |
| Academic hospital | 493 (64) | 233 (77) | 260 (55) |
| Community hospital | 98 (13) | 24 (8) | 74 (16) |
| Office | 160 (21) | 27 (9) | 133 (28) |
| Specialist cancer | 28 (4) | 17 (6) | 11 (2) |
| Caregiver characteristics | Overall (N=397) | Asia Pacific (n=214) | Europe (n=183) |
| Age, years, mean (SD) | 67.5 (9.8) | 64.2 (10.2) | 71.4 (7.5) |
| Female, n (%) | 282 (71) | 146 (68) | 136 (74) |
| Caregivers living with patient, n (%) | 299 (75) | 170 (79) | 129 (70) |
| Spouses as caregivers, n (%) | 270 (68) | 137 (64) | 133 (73) |

CIS, carcinoma in situ; ECOG, Eastern Cooperative Oncology Group; SD, standard deviation.

Symptom discordance

- All patients (100%) reported experiencing symptoms at time of data collection
- Physicians reported symptoms at time of data collection at a lower rate than patients (Figure 1). The most discordant reporting was for the following symptoms:
 - Frequent need to urinate (38% vs 52%)
 - Urinary urgency (27% vs 41%)
 - Fatigue (20% vs 31%)
- Similar trends were observed across Asia Pacific and Europe

References

1. Paolo G. et al, *Eur Urol* 2024;86(6):531-549. 2. Williams SB. et al, *JAMA Netw Open* 2021;4(3):e213800 3. Brausi M. et al, *Eur Urol* 2014;65(1):69-76. 4. Nayak A. et al, *Transl Androl Urol* 2021;10:2737-2749. 5. Yuen JW. et al, *Int J Environ Res Public Health* 2022;19(17):10825. 6. Anderson P. et al, *CMRO* 2008;24(11): 3063-3072. 7. Anderson P. et al, *CMRO* 2023;39(12): 1707-1715. 8. Babineaux SM. et al, *BMJ Open* 2016;6(8):e010352.

Study design

- Data were collected from the Adelphi Disease Specific Programme™ (DSP™): a cross-sectional survey of urologists/oncologists and their consulting patients⁵⁻⁸
- Patients' caregivers were also surveyed
- Physicians completed the surveys for 8 consecutive patients who consulted with them from July 2023 to April 2024

| Survey Participants | N |
|---------------------|-----|
| Caregivers | 397 |
| Physicians | 175 |
| Patients | 774 |
| Asia Pacific | |
| China | 259 |
| Japan | 42 |
| Europe | |
| Germany | 206 |
| Spain | 99 |
| France | 81 |
| Italy | 57 |
| UK | 30 |

Physician eligibility

- Urologists and oncologists actively involved in the management of patients with HR-NMIBC
- Spending ≥50% of their professional time in direct patient care
- Managing ≥6 patients with bladder cancer per month
- Willingness to participate in the survey

Patient eligibility

- Age ≥18 years
- A physician-confirmed diagnosis of HR-NMIBC (HG Ta/T1 or CIS)
- Diagnosed ≥12 months prior to the survey

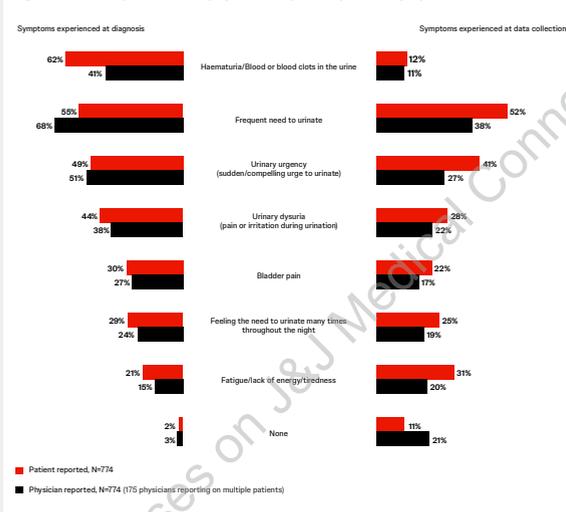
Caregiver eligibility

- Provided consent
- If caregiver's patient was included in the survey and met all eligibility needs

Survey

- Patients self-completed patient-reported outcome (PRO) measures: EuroQol 5-Dimension 5-Level (EQ-5D-5L), European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (EORTC QLQ-C30), EORTC Quality of Life Questionnaire Non-Muscle-Invasive Bladder Cancer24 (QLQ-NMIBC24), Work Productivity and Activity Impairment (WPAI), and questions on diagnosis and treatment experience
- Caregivers completed the Care-Related Quality of Life-7 dimensions (CarerQoL-7D) questionnaire and questions on their caregiver experience
- Physician-reported data included patient sociodemographic and clinical characteristics and symptom burden
- All data were stratified by region (Asia Pacific and Europe), and patients were matched to their treating physicians
- Patient- and physician-reported symptoms captured at diagnosis and during data collection were analyzed
- Descriptive statistics were used to summarize data
- Mean and standard deviation (SD) were reported for continuous variables; categorical variables were presented as frequency and percentages

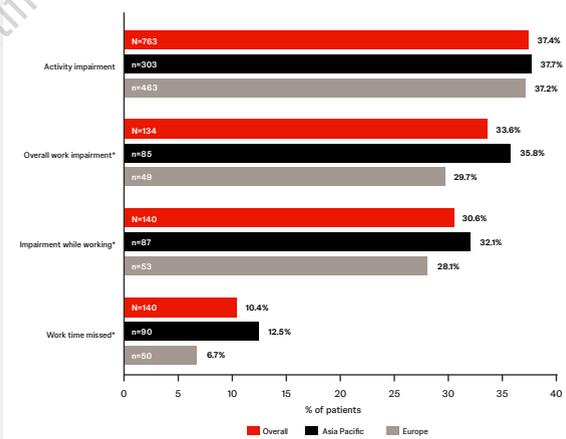
Figure 1: Overall patient- and physician-reported patient symptoms



WPAI

- Approximately one third of patients experienced some kind of activity impairment due to their HR-NMIBC, including impact to work (Figure 2)

Figure 2: Activity and work impairment due to HR-NMIBC



*Recorded only in working patients. WPAI, Work productivity and activity impairment.

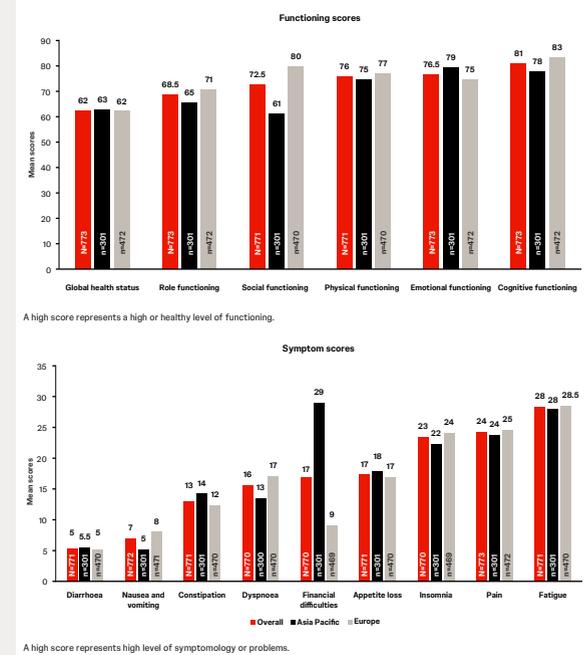
EQ-5D-5L

- Mean EQ-5D visual analogue scale scores were similar across regions (overall: 71.2, Asia Pacific: 71.6, Europe: 70.6)
- The EQ-5D-5L dimension scores indicated that:
 - Patients most frequently reported experiencing no or slight mobility and self-care problems
 - Over 50% of patients reported slight or moderate impact to usual activities, pain or discomfort, and anxiety or depression
 - Results were largely consistent across regions

EORTC-QLQ-C30

- Overall EORTC QLQ-C30 scores indicated patients had mild or moderate impairment across all functioning domains, with role functioning the most impacted overall (mean, 68.5)
- Social functioning was most impacted in Asia Pacific (mean, 61.2; Figure 3)
- Mean overall EORTC QLQ-C30 scores for symptom domains indicated patients experienced moderate levels of fatigue (28.3), pain (24.3), and insomnia (23.4)
- Financial difficulty was high in Asia Pacific

Figure 3: EORTC QLQ-C30 domain scores



EORTC-QLQ-NMIBC24

- Overall, male (mean, 40.5) and female (mean, 38.6) sexual problems and future worries (mean, 36.9) were the most impaired scoring domains (Table 2)

Table 2: EORTC QLQ-NMIBC24 symptom and function scores

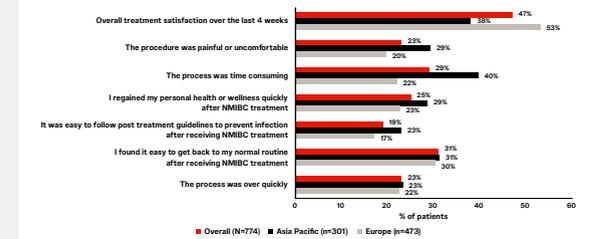
| | Mean (SD) | Overall | Asia Pacific | Europe |
|-------------------------------|-----------|--------------|--------------|--------------|
| Urinary symptoms | | N=771 | n=301 | n=470 |
| | | 26.7 (17.26) | 25.0 (17.69) | 27.9 (16.90) |
| Malaise | | N=771 | n=301 | n=470 |
| | | 15.4 (17.42) | 19.4 (18.20) | 12.8 (16.40) |
| Future worries | | N=772 | n=301 | n=471 |
| | | 36.9 (24.87) | 38.7 (21.97) | 35.8 (26.52) |
| Bloating and flatulence | | N=771 | n=301 | n=470 |
| | | 16.3 (17.57) | 21.3 (18.84) | 13.2 (17.31) |
| Sexual function | | N=759 | n=288 | n=461 |
| | | 16.6 (21.68) | 16.7 (20.33) | 16.6 (22.54) |
| Male sexual problems | | N=559 | n=233 | n=326 |
| | | 40.5 (33.77) | 43.7 (35.13) | 38.2 (32.62) |
| Intravesical treatment issues | | N=764 | n=300 | n=464 |
| | | 27.2 (25.27) | 30.9 (25.75) | 24.9 (24.68) |
| Sexual intimacy | | N=381 | n=130 | n=251 |
| | | 24.1 (28.93) | 20.8 (24.30) | 25.9 (28.09) |
| Risk of contaminating partner | | N=375 | n=128 | n=247 |
| | | 24.7 (26.25) | 32.8 (28.06) | 20.5 (24.27) |
| Sexual enjoyment | | N=369 | n=128 | n=241 |
| | | 34.5 (27.39) | 34.1 (24.20) | 34.7 (28.99) |
| Female sexual problems | | N=63 | n=23 | n=40 |
| | | 38.6 (30.06) | 36.2 (24.44) | 40.0 (33.08) |

SD, standard deviation.

Patient perspective on treatment experience

- Overall,
 - 31% of patients found it easy getting back to their normal routine following treatment
 - 29% of patients found the treatment process time-consuming
 - 25% of patients regained their health quickly post-treatment
 - 23% of patients reported experiencing pain or discomfort during the procedure
 - 19% of patients found it easy to follow post-treatment guidance (Figure 4)
- Less than half (47%) of patients were satisfied with overall treatments over the last 4 weeks (Europe: 53%, Asia Pacific: 38%)

Figure 4: Patient experience with HR-NMIBC treatment



Caregiver burden

- The majority of caregivers experienced 'some' (53%) or 'a lot' (7%) of problems combining care tasks with daily activities
- Caregiver burden was high in the Asia Pacific region
- 37% of caregivers reported that the patient's bladder cancer moderately impacted their daily life
- Caregivers reported their social life was most affected (Europe: 32%, Asia Pacific: 41%)

Limitations

- Cross-sectional survey design, variation among patient treatment, time since diagnosis, etc. limit drawing conclusions about causal relationships
- Retrospective survey of symptoms reported at diagnosis
- Patients who consult frequently with their physicians may be over represented in the survey
- Missing patient data were excluded from analyses and not imputed

