Experiences of treatment and care provided for metastatic castrate resistant prostate cancer (mCRPC) in the UK

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BACKGROUND: Appraisals of information needs, expectations and experiences of treatment in prostate cancer have highlighted the lack of relevant data in advanced disease.

EXTREQOL (EXperiences of TREATment and Quality Of Life) is a 6 month longitudinal observational study examining QoL, treatment experiences and information needs from the patients’ and healthcare professionals’ perspectives, and from interviews with a subgroup of patients & their partners.

AIMS: explore in more detail the impact of treatment (Rx) and care on quality of survival (QoS).

METHODS: structured interviews in-person or by phone.

Interviews: ≤14 days of initiating systemic Rx for mCRPC
- repeated after 3-months Rx
- patients & partners interviewed separately
- most questions had pre-assigned response categories
- replies to open-ended questions were written verbatim

Areas covered: demographics & medical history, experiences of Rx decisions, symptoms and Rx-related side effects (SEs), information provision, perceived benefits and harms of Rx, impact of Rx and care on the lives of patients & partners.

Participant details: 33 patients, married to their partners and 4 single men were recruited from 15/20 cancer centres.

Patients: mean 75.6yrs (min-max 56-91yrs)
- single men were older
- 22% (8/37) presented with mCRPC for the first time
- 60% (22/36) disease had spread to bone, 8 visceral, 6 both
- Rx for mCRPC were: enzalutamide (13), abiraterone (7), docetaxel (9), radium (5), cabazitaxel (2), & goseralin (1)
- concurrent Rx: hormone injections (34), bisphosphonates (12) analogies (18) & radiotherapy for bone metastases (4)

Partners: all female, mean 67.6yrs (min-max 54-79yrs).

RESULTS (1): PAIN AT PRESENTATION
- pain was the worst symptoms for a majority (43%)
- 51% needed to discuss pain management
- 19% attributed their pain to non-cancer origins

“my pain in the lower back and shoulders is due to degeneration” (P1, 72yrs)
“I put the backache down to gardening” (P33, 72yrs)
“pain in my hip could be rheumatic” (P14, 56yrs)

“54% said Rx was a shared doctor-patient decision”
“87% felt spouses were integral to decision-making”

RESULTS (2): INFORMATION PROVISION

INFORMATION SOURCE

<table>
<thead>
<tr>
<th>INFORMATION SOURCE</th>
<th>Married men (33)</th>
<th>Single men (4)</th>
<th>Spouse (33)</th>
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<tbody>
<tr>
<td>Clinician discussed SEs</td>
<td>29</td>
<td>1</td>
<td>29</td>
</tr>
<tr>
<td>LEAFLETS received</td>
<td>drug company</td>
<td>16</td>
<td>2</td>
</tr>
<tr>
<td>Macmillan</td>
<td>15</td>
<td>1</td>
<td>13</td>
</tr>
<tr>
<td>hospital own</td>
<td>8</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>CRUK</td>
<td>3</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>other</td>
<td>2</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>None</td>
<td>3</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>WEBSITES recommended</td>
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<td>4</td>
<td>0</td>
</tr>
<tr>
<td>CRUK</td>
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<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Prostate Cancer UK</td>
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<td>0</td>
<td>1</td>
</tr>
<tr>
<td>None</td>
<td>29</td>
<td>4</td>
<td>31</td>
</tr>
<tr>
<td>Internet searched for more information about SEs</td>
<td>11</td>
<td>0</td>
<td>18</td>
</tr>
</tbody>
</table>

RESULTS (3): UNDERSTANDING OF Rx AIMS

= patients & partners

<table>
<thead>
<tr>
<th>AIMS</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>to slow cancer</td>
<td>60</td>
</tr>
<tr>
<td>improve QoL</td>
<td>55</td>
</tr>
<tr>
<td>extend life</td>
<td>55</td>
</tr>
<tr>
<td>alleviate pain</td>
<td>55</td>
</tr>
</tbody>
</table>

RESULTS (4): EXPERIENCE AFTER 3 mths Rx

- 33% had recently had a pain management discussion
- fatigue was worst Rx-related SE for a majority (43%)
- 27% experienced unexpected SEs
- 54% had sought help for their SEs
- 46% had NO access to a prostate cancer (PCa) nurse in clinic

“no opportunity to discuss my incontinence with a nurse” (P13, 69yrs)

RESULTS (5): SUPPORTIVE SERVICE USE (low utilization)

- 54% of the men had no interest in joining a support group
- it was evident male values hindered help-seeking

CONCLUSIONS

- achieving optimal QoS is challenging
- essential PCa nurse & palliative care resources increase to enable pain & other symptom amelioration
- clinicians need to be aware of men’s reluctance to report pain, and/or attribute it to other ailments
- dedicated mCRPC clinics are warranted

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