Patients’ and partners’ views of treatment and care provided for metastatic castrate resistant prostate cancer (mCRPC) in the UK

S.L.Catt1, L.Matthews1, H.Payne2, M.D.Mason3, V.Jenkins1

1SHORE-C, Brighton & Sussex Medical School (BSMS), 2University College Hospital London, 3Cardiff University School of Medicine

BACKGROUND: Appraisals of information needs, expectations and experiences of treatment in prostate cancer have highlighted the lack of relevant data in advanced disease. EXTREQUAL (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: demography & 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 quality of survival (QoS).

RESULTS (1): PAIN AT PRESENTATION

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

Participant details: 33 patients, married to their partners and 4 single men were recruited from 15/20 cancer centres. All female, mean 67.6yrs (min-max 54-79yrs).

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), & goserinil (1)
- concurrent Rx: hormone injections (34), bisphosphonates (2) analgesics (18) & radiotherapy for bone metastases (4)

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

RESULTS (2): INFORMATION PROVISION

<table>
<thead>
<tr>
<th>INFORMATION SOURCE</th>
<th>Married men (33)</th>
<th>Single men (4)</th>
<th>Spouse (33)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinician discussed SEs</td>
<td>29</td>
<td>1</td>
<td>29</td>
</tr>
<tr>
<td>LEAFLETS received</td>
<td>16</td>
<td>2</td>
<td>15</td>
</tr>
<tr>
<td>drug company</td>
<td>15</td>
<td>1</td>
<td>13</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>
</tbody>
</table>

RESULTS (3): UNDERSTANDING OF Rx AIMS

RESULTS (4): EXPERIENCE AFTER 3 mths Rx

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
- Partners/family provide core of support & need help too
- Dedicated mCRPC clinics are warranted

54% had NO access to a prostate cancer (PCa) nurse in clinic
- 46% had NO access to a prostate cancer (PCa) nurse in clinic
- 27% experienced unexpected SEs
- 54% had sought help for their SEs
- 19% attributed their pain to non-cancer origins
- 16% had a worse SE since initiating Rx
- 33% had recently had a pain management discussion
- 19% had a different viewpoint to clinicians
- 54% had NO access to a prostate cancer (PCa) nurse in clinic

“he doesn’t like to look weak and ask for help” (S6, 69yrs)
“I think not wanting to have help from the hospice might be a male thing, wanting to keep going on your own” (P2, 68yrs)
“I prefer to keep things in the family” (P4, 69yrs)

“my 20yr old son’s taken it badly, my wife is my rock, I’m very concerned, they need support too” (P14, 56yrs)

“he doesn’t like to look weak and ask for help” (S6, 69yrs)
“I think not wanting to have help from the hospice might be a male thing, wanting to keep going on your own” (P2, 68yrs)
“I prefer to keep things in the family” (P4, 69yrs)

“my 20yr old son’s taken it badly, my wife is my rock, I’m very concerned, they need support too” (P14, 56yrs)

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

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

“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)

19% attributed their pain to non-cancer origins

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

46% had NO access to a prostate cancer (PCa) nurse in clinic
- 27% experienced unexpected SEs
- 54% had sought help for their SEs
- 19% attributed their pain to non-cancer origins
- 16% had a worse SE since initiating Rx
- 33% had recently had a pain management discussion
- 19% had a different viewpoint to clinicians
- 54% had NO access to a prostate cancer (PCa) nurse in clinic

“he doesn’t like to look weak and ask for help” (S6, 69yrs)
“I think not wanting to have help from the hospice might be a male thing, wanting to keep going on your own” (P2, 68yrs)
“I prefer to keep things in the family” (P4, 69yrs)

“my 20yr old son’s taken it badly, my wife is my rock, I’m very concerned, they need support too” (P14, 56yrs)

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

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

“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)