

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.

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: 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 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), & goserelin (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 (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)

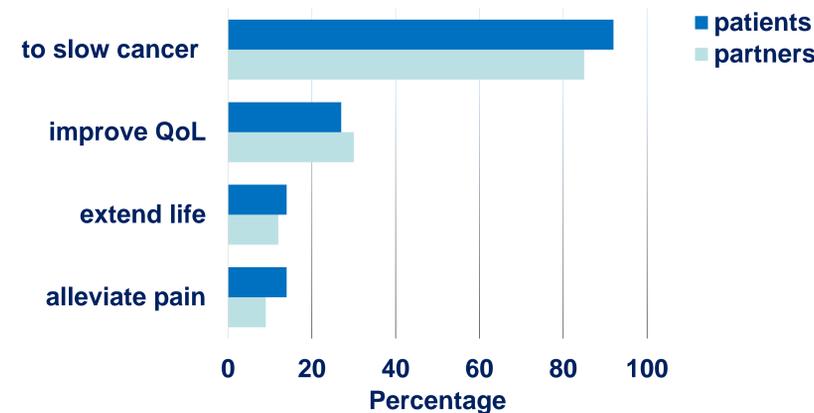
"pain in my hip could be rheumatic" (P14, 56yrs)

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

RESULTS (2): INFORMATION PROVISION

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

RESULTS (3): UNDERSTANDING OF Rx AIMS

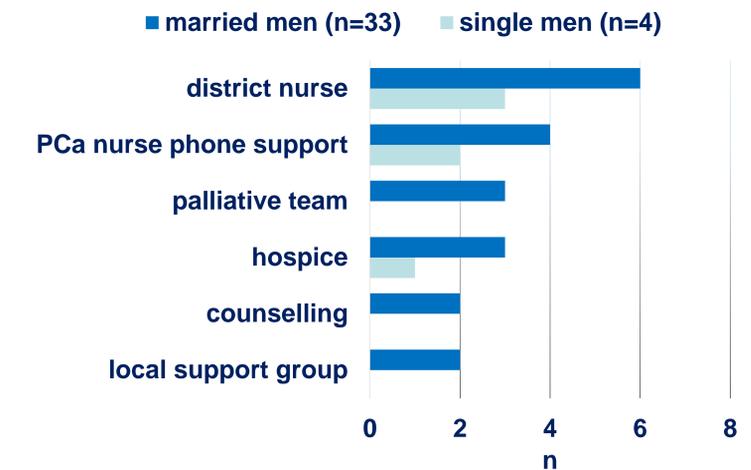


RESULTS (4): EXPERIENCE AFTER 3 mths Rx

- ❖ 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

"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)

- ❖ appeals for partners/family to be supported were apparent

"I feel particularly unsupported, I don't feel carers are supported enough" (S22, 57yrs)

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

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