

## Background

Men with prostate cancer (PC) may need to make multiple decisions about treatments over the course of their disease. For many, PC will ultimately progress and become hormone refractory or castrate resistant (CR). Drugs such as docetaxel, enzalutamide, abiraterone and cabazitaxel may be offered if available, until supportive care for symptoms remains the only option. We investigated sources of information provided to aid the decision-making of men with metastatic CRPC (mCRPC) and examined healthcare professionals' (HCPs) views about issues that guided treatment choices.

## Methods

- Two reviews about the quality of life (QoL) & information needs/resources available for men with mCRPC were conducted
- Oncologists & nurses specialising in urology were interviewed about:-
  - definitions of CRPC/mCRPC & terminology used with patients (pts)
  - content of discussions around mCRPC diagnosis & treatments
  - worst treatment related side effects (SEs)
  - how SEs are captured routinely in clinic
  - information materials that they provide to their pts
  - questions that pts & partners ask HCPs
  - priorities for improving mCRPC patient care
- UK charity websites & booklets were examined for information on CRPC/mCRPC & ease of searching using those terms on 28/04/15

## Literature Reviews

We addressed 3 questions:

- what are the information needs of men with mCRPC & their families?
- what is the utility of information resources available?
- what impact do different trial treatments have on QoL/pain palliation?

### (1) Information needs

Only 3 full text articles met our inclusion criteria [1-3]. The unmet needs identified were:

- treatments & associated SEs
- progression of the disease (end of life expectations)
- available supportive care services

### (2) Information resources

No academic publications met our inclusion criteria as they did not explicitly categorise pts as having mCRPC. Most available resources were appropriate for men considering prostate cancer screening/early stage disease & treatment. There was little evidence demonstrating effectiveness of information supplied.

### (3) Quality of life/pain palliation

There were 14 articles showing the impact of trial treatments on QoL/pain palliation but only 7 used appropriate pt reported outcome (PRO) measures and/or provided sufficient evidence that treatments had improved pts' QoL and/or reduced pain [4-7].

## HCPs' Views

Interviews with oncology consultants (8 clinical, 1 medical) & 4 specialist nurses (3 female, 1 male) revealed :-

- Although terms CRPC/mCRPC are common in patient information sheets about clinical trials & in the medical literature, this was rarely used when talking to pts; advanced prostate cancer or Hormone Refractory PC was preferred

*"there has been this big movement by the prostate cancer charities and the support groups **not** to use the word castrate. So in the UK, and what NICE are now saying, is hormone independent PC"*

- Lack of a clear pathway in many hospitals for identification of new mCRPC pts
- HCPs views on worst treatment related SEs for pts were:-
  - chemotherapy:** fatigue, peripheral neuropathy, neutropenic sepsis, hair loss,
  - enzalutamide:** fatigue, nausea
  - abiraterone:** peripheral oedema, nausea
  - radium 223:** pain flares, persistent nausea
  - steroids:** bruising, bodily changes, muscle weakness
- SEs were not systematically collected & PRO measures rarely used in clinic
- HCPs notice a reluctance by pts to mention bad SEs

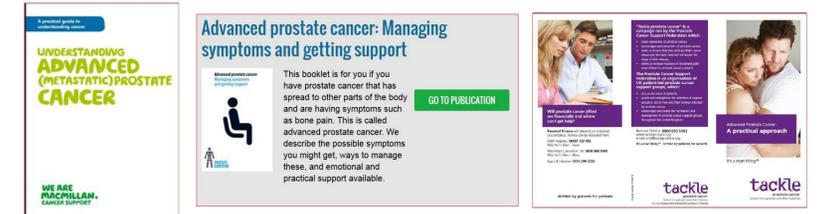
*".....fixated on their PSA coming down, so worry that if they report side effects we'd stop their treatment or reduce treatment"*

- Family rarely knew what to expect as the disease progressed, especially with the mixed messages provided at initial diagnosis particularly the often quoted comment

*"A lot of the information about prostate cancer is around many men die of something else, they live for many years, so expectation is yes I understand this is bad news but this information talks about 10-15 years why are you saying it might be a lot shorter ..."*

- Nurses believed men with mCRPC were an underserved group
- Most common problem for men identified by nurses was managing their changing roles within the family & society
- Priorities for future care included: more specialist nurses; access to treatments; limiting toxicity; electronic capture of QoL data; & getting back to work
- Clinicians were aware of the local support groups but did not always give pts information about them
- The written materials & website details most frequently given to pts were those of Macmillan and Prostate Cancer UK

## Terms used/ information in UK Cancer Charity Materials



- The Charity websites did not use the term CRPC/mCRPC, unless in reference to clinical trial materials, or specific drug information
- Pts occasionally used the phrase in forums and blogs
- Prostate Cancer UK** was the only website to give the same reference information irrespective of search term used 'Hormone Resistant PC' /Hormone Refractory PC, advanced prostate cancer, CRPC, or mCRPC'
- Macmillan & Cancer Research UK** use 'Hormone Refractory PC'
- Prostate Cancer UK** use 'advanced metastatic disease'
- Tackle** preferred 'Hormone Relapsed PC' but noted that the medical profession sometimes use the term 'CRPC' or 'Hormone Resistant PC'
- The Charity booklets generally provided lots of useful information for pts & families & downloadable leaflets on individual drugs, research & treatment options for when PC has spread

## Conclusions

- Reviews showed the need for much more evidence based research into the specific needs of men with mCRPC & their families
- As the primary therapeutic aim in mCRPC is to delay progression & to palliate symptoms, it is surprising how infrequently PRO data are collected in clinic & reported appropriately in treatment trials
- Specific prostate cancer Charity websites offer good information but not all use the term mCRPC or define it, which could be confusing
- Oncologists and specialist nurses are aware of the shortcomings in treating and caring for men with mCRPC and their families

## Review References

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