PERCEPTIONS AND EXPERIENCES OF PATIENTS WITH HORMONE-RELAPSED PROSTATE CANCER: A UK CASE STUDY

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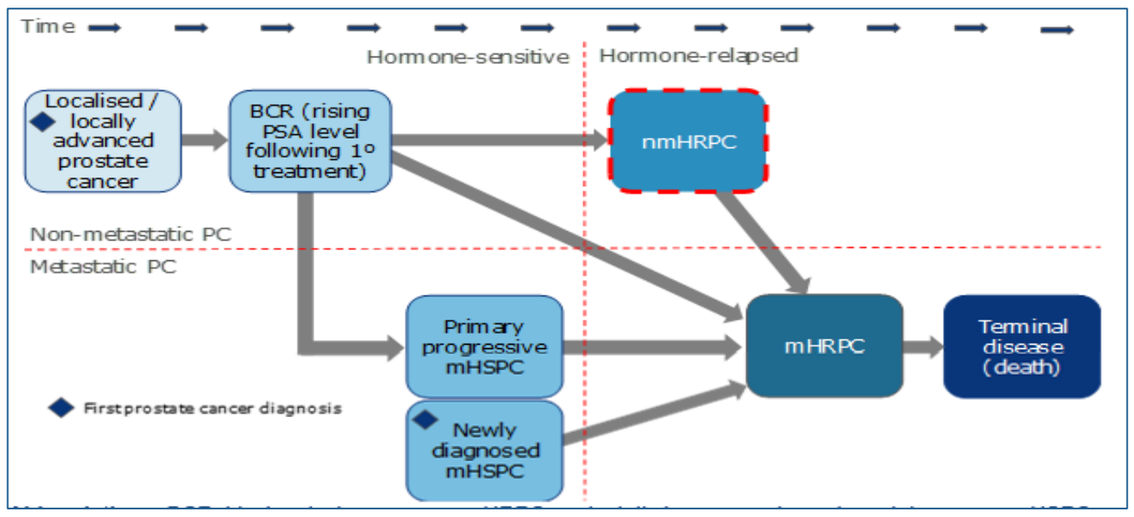
Background

Prostate cancer (PC) is the most common cancer in males in England(1). Between 2015 and 2016, there were 40,489 new cases of PC in the UK, of these, 84% of men had non-metastatic disease at diagnosis(1-3). A typical man is diagnosed with PC in his late 60's; the choice of primary therapy in the UK is determined by the patient's risk category and stage of disease - localised, locally-advanced (LPC/LAPC), or metastatic -, and may include radical prostatectomy, radiotherapy or androgen deprivation therapy (ADT)(4,5). For most men diagnosed with LPC/LAPC, primary therapy is curative. However, approximately one third of men experience biochemical recurrence (BCR) i.e. rising prostate specific antigen (PSA) levels(5). For men with BCR, NICE recommends a calculation of PSA doubling time (PSADT) to assess the risk of developing metastases. Men with rapidly rising PSA levels (PSADT ≤3 months) may be offered ADT (achieved by surgical or medical castration) to suppress tumour growth. Although ADT is initially effective, men typically develop resistance to ADT in two to three years, indicating that ADT is no longer effective at controlling disease progression(5,6). Hormone-relapsed prostate cancer (HRPC) is defined by rising PSA levels whilst receiving ADT, despite castrate levels of testosterone. If no metastases are detected, the patient is described as having non-metastatic hormone-relapsed prostate cancer (nmHRPC). Men with nmHRPC are typically asymptomatic or experience mild symptoms that may not substantially affect health-related quality of life (HRQoL). However, since ADT is no longer able to control disease progression, these men are likely to develop metastatic disease, which is associated with severely debilitating symptoms, rapidly declining HRQoL and poor overall survival (OS). Figure 1 depicts the disease progression in PC.

Figure 1: Prostate cancer disease progression



Abbreviations: BCR: biochemical recurrence; mHRPC: metastatic hormone-relapsed prostate cancer; mHSPC: metastatic hormone-sensitive prostate cancer; nmHRPC: non-metastatic hormone-relapsed prostate cancer; PSA: prostate-specific antigen.

Objective

Prostate cancer is shifting to a chronic condition due to the availability of innovative medicines. Previous studies have explored the impact of HRPC on quality of life, however the perspectives and experiences of patients in the UK have not been explicitly considered(7). The objective of this study was to explore the experiences and preferences of UK patients with HRPC. More specifically, to understand:

- The experience of being diagnosed with prostate cancer
- The impact of prostate cancer on daily life

Methods

A focus group discussion was conducted to gather insights from participants. Participants were recruited through a prostate cancer patient group in England and Wales. All participants meeting the following criteria were invited:

1. Men with non-metastatic prostate cancer who:
   - have undergone orchiectomy (a surgery to remove the testicles)

   or
   - are currently receiving long-term, medication-based ADT

   and
   - who have been informed that their PSA levels are rising
2. Men who previously had non-metastatic cancer and were on ADT, but have now been diagnosed with metastatic prostate cancer

The workshop included four men (consent obtained) aged 64–77 years, two with a diagnosis of nmHRPC and two with a current diagnosis of mHRPC. Demographic and health information for the patients are presented in Table 1. An independent facilitator moderated the discussion by asking participants structured questions centred around 4 key themes, based on a similar study conducted in non-UK patients(7). To assess the impact of PC on quality of life, participants were asked to complete the Functional Assessment of Cancer Therapy-Prostate (FACT-P) questionnaire.

Results

Themes discussed included diagnosis, symptoms and impact of nmHRPC and mHRPC, and treatment experiences and preferences:

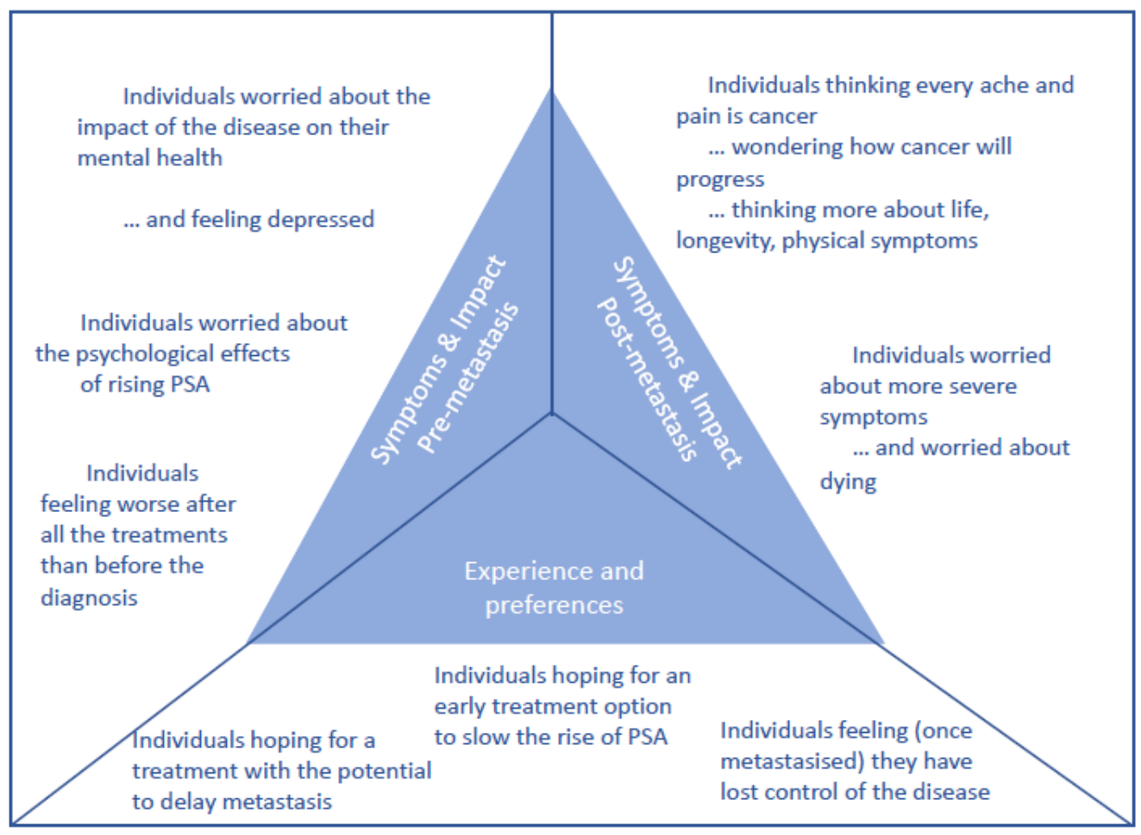
- Participants highlighted culture and lack of public understanding of the disease as key to the relatively low disease awareness and delayed diagnoses of prostate cancer in the UK.
- The psychological and emotional impacts of nmHRPC on participants' lives were identified as great, if not greater, than the physical impacts (see Figure 2).
- Neither of the two participants diagnosed with mHRPC had experienced new or worsening physical symptoms since the diagnosis of metastasis, however both noted increased emotional burden and one, thoughts of death (see Figure 2).
- All participants concluded that, hypothetically, they would take/would have taken a treatment that delays the onset of metastasis if it were available (see Figure 2).
- Self-reported cancer severity ranged from intermediate to severe; FACT-P scores were 98–139 (see Table 1)

Table 1: Participant demographics and health information

	Participant 1	Participant 2	Participant 3	Participant 4
Age	77	64	69	72
Disease stage	Non-metastatic	Non-metastatic	Metastatic	Metastatic
Self-reported cancer severity	Intermediate	Locally advanced, with a rising PSA	Stable lymphatic disease, 6 bone metastases	Severe
Year of diagnosis	nmHRPC: 1995	nmHRPC: 2014	nmHRPC: 2010 mHRPC: 2018	nmHRPC: 2010 mHRPC: 2018
FACT-P[a] score	120	99	139	98

[a] Participants were asked to complete the Functional Assessment of Cancer Therapy-Prostate (FACT-P) questionnaire (a relevant, worldwide tool used for assessing the health-related quality of life in men with prostate cancer) at the start of the workshop.

Figure 2: Experience and preferences of individuals with HRPC



Conclusions

The aim of this study was to gain insights into the experiences and preferences of individuals with HRPC in the UK. The study found that receiving a diagnosis of prostate cancer can be overwhelming. HRPC impacts numerous aspects of UK patients' lives - physically, emotionally and socially.

Further qualitative studies are needed in the UK, of bigger sample size and greater complexity, to explore in detail the emotional responses of men with HRPC diagnosis, the emotional burden on family, friends and social life, and to gain a better understanding of their perspectives in regard the management of treatment in the NHS and their preferences for treatment.

Key Findings

The findings of this study supports those of previous studies;[7] progression to mHRPC and the development of severe symptoms negatively affects patients' lives emotionally, physically and socially. In this study, patients indicated that they would have taken medication to delay metastasis if this had been available, even if they were asymptomatic. As found in previous studies[8], patients place substantial value on avoiding the development of metastases and treatment with chemotherapy. The findings indicate that the hypothetical option to receive active treatment to prolong the non-metastatic state is expected to alleviate patient fear and anxiety of disease progression.

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