‘Survivorship’ in prostate cancer II: the need for ongoing patient support

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With increasing numbers of men living with prostate cancer for many years, there is a growing need for improved support in the long term.

It has recently been predicted that by 2020 almost half the UK population will develop some form of cancer during their lifetime – and at least four in every ten of them will survive. Inevitably then, the requirement for care and support of all these very many cancer survivors will pose a Herculean challenge for both society and the NHS over the decades to come. Cancers were responsible for 157,000 deaths in the UK in 2010, but at least as many people will have survived the disease. These people will have been left with a variety of complex needs, to which health services, particularly in primary care, will need to respond.

Patients often refer to the experience of being diagnosed and treated for cancer as a ‘rollercoaster ride’. The emotions that they go through include shock, anger, fear, anxiety, relief and acceptance – all of these can have a huge impact, physically and emotionally. The nature of their relationships may be irrevocably changed and their self-esteem undermined. Provision of ongoing support throughout the ‘cancer journey’ can have an enormous impact on the quality of life not only of the patients, but also of their partners, friends and relatives. That is what survivorship is all about.

‘Survival’ following a diagnosis of prostate cancer poses a variety of challenges not only for the sufferer, but also for all those who care for him. These vary according to the grade and stage of the cancer at the time of diagnosis, which in turn will influence the type of treatment, and consequently the side-effects encountered afterwards. Unlike women who suffer from breast cancer, men with prostate cancer often fail to benefit from support from other sufferers to share experiences and help one another. One explanation for this is the well-known reluctance of men to reach out to each other in times of trouble, for fear of appearing weak or unmanly.

PERSISTING WITH ACTIVE SURVEILLANCE

Increasingly, so-called ‘low-risk’ prostate cancer (Gleason 3+3=6) is managed by ‘active surveillance’, whereby treatment is

A CT scan showing liver metastases from prostate cancer

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deferred until signs of disease progression occur, such as a rise in PSA, or deterioration of MRI or prostate biopsy findings. Although no physical side-effects flow from active surveillance, the psychological burden of knowing that one’s prostate contains a cancer should not be underestimated. Some men find this ‘sword of Damocles’ difficult to deal with, and consequently seek more aggressive treatment.

Ongoing counselling support of patients undergoing active surveillance can help men persist with the protocol – this is of value, particularly as there is evidence that two-thirds of men who are managed in this way will turn out never to require either surgery or radiotherapy.

SUPPORT FOR MEN WITH INTERMEDIATE-RISK PROSTATE CANCER
Intermediate-risk (Gleason 3+4=7) prostate cancer is often treated by total prostatectomy, increasingly by means of minimally invasive technology, including robotics. Postoperatively, men undergoing this type of surgery will need temporary advice about urinary continence. Stress incontinence on coughing and sneezing, requiring pads, is common for a few weeks after the procedure, but usually resolves rapidly. Only rarely now is a urethral sling operation or implantation of an artificial urinary sphincter required to resolve persistent urinary leakage.

Erectile dysfunction (ED) after radical prostatectomy is very common initially, but slowly improves with time, provided that at least one of the two neurovascular bundles is spared. Evidence is mounting that early treatment with a phosphodiesterase-5 inhibitor, such as tadalafil (Cialis) 5mg/day or sildenafil (Viagra) 25 or 50mg/day, can facilitate eventual recovery of normal erectile function. In addition, patients often find the use of a vacuum device and/or prostaglandin E1 therapy helpful, either by MUSE intraurethral suppositories or intracavernosal injection. Patients should be informed about the possibility of ED, as well as the permanent lack of ejaculation, before their operation. Counselling support, and in particular tuition about self-injection techniques, can be very helpful, and are often much appreciated by patients and their partners. Clinical nurse specialists are often best placed to provide this important supportive role.

ADVICE FOR MEN WITH HIGH-RISK CANCER
Higher-risk cancers (Gleason >8, PSA >20ng/ml, clinical stage T3b) are often managed with a combination of androgen ablation and external beam radiotherapy (EBRT). A subset of patients in whom the cancer appears clinically confined to the prostate may be suitable for surgery, but they should be warned that they may need to undergo postoperative radiotherapy.

Recently, mutations of the BRCA1 and 2 genes have been linked to more aggressive prostate cancers. Patients with a strong positive family history may require genetic counselling.

Androgen ablation is usually achieved with a combination of androgen receptor blockade induced by a luteinising hormone-releasing hormone (LHRH) analogue, such as goserelin or leuprorelin, or an LHRH antagonist, such as degarelix. Because LHRH analogues result in a transient stimulation before they block testosterone production by the testes, patients are prescribed an antiandrogen, such as bicalutamide, for a few weeks before and after their first injection.

News about the presence of metastatic disease should be conveyed sympathetically, and include the message that the prognosis is improving. The side-effects of androgen ablation are well known and are the subject of a series of articles scheduled for publication in Trends during 2013. They need to be explained to patients carefully. Loss of libido, ED and hot flashes are the most troublesome of these in the short term. Here again, counselling support may help to reduce anxiety.

In the longer term, deterioration of bone health, central obesity and the metabolic syndrome are also concerns that need to be discussed. Some patients become depressed and suffer other psychological consequences as a result of androgen suppression. In such a situation, switching from an LHRH analogue to an oral antiandrogen, such as bicalutamide, should be considered. Patients need to be aware, however, that, because of the rise in oestrogen levels that accompanies the androgen receptor blockade induced by bicalutamide, bilateral gynaecomastia is likely to develop. The use of nipple irradiation to prevent this is seldom employed these days because of concerns about inducing male breast cancer. Instead,
tamoxifen in small doses is prescribed in some patients and seems quite effective. Other strategies include intermittent androgen ablation regimens to reduce the incidence of side-effects.

Unfortunately, after a variable interval, most patients in remission as a result of androgen ablation therapy suffer a relapse, and this is usually heralded by a rise in previously suppressed PSA levels. Unsurprisingly, patients and their families are often alarmed by this development. Counselling support at this juncture is therefore appreciated. Fortunately, in addition to chemotherapy, there are now two new therapeutic options: firstly abiraterone, which is usually administered in conjunction with a low dose of prednisolone, and secondly enzalutamide. At the time of writing, only the former has been approved by the regulatory authorities, but enzalutamide will become available very soon. These agents have both been shown to improve survival of men with castration-resistant prostate cancer while producing only modest side-effects.

LEARNING FROM BREAST CANCER SUPPORT SERVICES
The disparity between support services, including genetic counselling, available for men with prostate cancer, compared to those provided for women with breast cancer, is an ongoing matter of concern. However, useful lessons can be learned from the latter, which are often provided by charities such as Breakthrough Breast Cancer or Breast Cancer Care.

Better information, either written or provided by a helpline or through the internet, for newly diagnosed men, and for those whose cancer is progressing, is now becoming more widely available. Charities such as Prostate Cancer UK are working assiduously to remedy this situation by providing more easily understandable information, building support networks and recruiting more prostate cancer nurse specialists. Closer working of Prostate Cancer UK with the British Association of Urological Surgeons and the British Association of Urological Nurses should help to make the prostate cancer journey a better supported, less harrowing affair.

REFERENCES