Testing care pathways for prostate cancer survivors

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Prostate cancer is the most common cancer in men in the UK, with around 38,000 new cases diagnosed each year (Cancer Research UK, 2011). However, while rates have almost tripled over the last 30 years, there has not been a corresponding increase in mortality. For patients diagnosed with prostate cancer during 2002-04, the five-year survival rate in 2009 was 82% (Cancer Research UK, 2011).

Much of the increase in diagnosis is due to incidental discovery of prostate cancer following transurethral resection of the prostate (TURP) and, more recently, the prostate specific antigen (PSA) testing. The current model of care is based on a traditional “one size fits all” model and focuses on the disease rather than the individual. As a result, patients and carers feel they do not have all the information, advice and support that would help with self-management (Ipsos MORI, 2011).

As demand on the NHS increases, it will not be possible to deliver this disease-driven model of care. Traditional follow-up clinics do not meet patients’ needs because time and resource constraints mean many have become test-result clinics. A rapid review of practice across cancer networks in England found this system lacks consistency between providers and, in some instances, within organisations (NHS Improvement, 2011).

While this does not mean that follow-up clinics have no place in the future NHS, they do have to become more targeted to the needs of those who need follow-up and where other forms of managing the condition are not appropriate.

Nurses have a pivotal role in supporting the shift from the traditional model to one that helps patients help themselves. This will, for many, require a shift from professional-led assessment to using motivation techniques to support patients, where appropriate, to manage themselves.

North Bristol Trust sees around 550 patients with newly diagnosed prostate cancer each year. It has an established enhanced recovery programme with successful nurse-led follow-up clinics for prostate cancer. The survivorship programme developed includes health and wellbeing courses and an in-house self-management programme to further build patients’ capability to self-manage, depending on ability.

The new pathway aims to improve support to enable patients to self-manage and give them confidence about using the remote monitoring system.

The trust has a lead role in supporting the development of a national system of remote monitoring. Plans include looking at the options for hand-held records for patients with cancer, so essential information on their treatment is to hand.

Emma Elliott, Macmillan uro-oncology nurse specialist at the trust, said: “As a team of nurse specialists, our roles now incorporate the organising, running and delivery of the living well days and self-management programmes for patients with prostate cancer. “Patients’ pathways are changing positively and the feedback from these events is extremely encouraging.”

1 Prostate cancer is the most common cancer in men in the UK
2 The current model of care focuses on the disease rather than the individual
3 Nurses have a pivotal role in supporting the shift from the traditional model to one that helps patients help themselves
4 With stratification, patients agree the care pathway in partnership with the clinical team
5 Some common principles underpin this new approach to care

Keywords: Prostate cancer/Cancer survivorship/Care pathways

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Abstract Frew G, Dashfield E (2012) Testing care pathways for prostate cancer survivors. Nursing Times; 108: 13, 30-31. Although prostate cancer incidence rates have risen sharply over the last 30 years, the survival rate is also high.

New pathways of care are needed to support patients, where appropriate, to self-manage. This article describes a project that is testing risk-stratified care pathways and nurses’ role in this new model of care.

Transrectal ultrasound scan of the prostate showing cancer

Nursing Practice Innovation Cancer survivorship

Care should focus on the individual rather than the disease. A risk-stratified care pathway is being tested to meet people’s needs and encourage self-management.
Principles for future care
Delivering this new model of care involves taking a whole-system approach to care delivery as a “package”, which requires a redesign of care pathways. Stratification is the process where patients living with and beyond cancer agree in partnership, with the clinical team, the care pathway that will meet their ongoing needs. In essence, this will involve:

- A professional clinical team-led model for complex patients;
- A supportive patient and professional model for those unable to self-manage;
- A patient self-managed model where they have been equipped to manage their own care, with monitoring of ongoing tests and the assurance of direct access if problems occur.

Whether the pathway is professionally led or patients self-manage with support, it is underpinned by some common principles.

The key principles for care following treatment for prostate cancer are:

- Patients are stratified to a pathway that meets their individual needs;
- Care coordination provides the “umbrella” to ensure that effective care is delivered by the right person in the right place at the right time;
- All patients should be offered an assessment and written care plan that meets their needs and supports them to manage themselves;
- Patients should be given named health professional contacts in case any issues arise or further advice is needed. This is likely to be a prostate cancer nurse specialist, although, if the matter is related to a particular need, such as erectile dysfunction, it may be a named contact for that specific issue;
- They should receive a treatment/care summary that includes the disease and its stage, treatment given, signs and symptoms to look out for and any post-treatment instructions (this may be part of the written care plan);
- Information, advice and support tailored to the individual should be provided, to give patients the confidence to self-manage and the ability to seek support as needed;
- Information on services that could help meet their needs, such as community or voluntary organisations;
- A safe and effective system for monitoring patients’ PSA levels and timely access to specialist advice and support (direct access; triggered by patient or professional).

The National Cancer Survivorship Initiative (NCSI) aims to address the needs of patients living with and beyond cancer. This focuses on the coordination of care and includes assessment and care planning, ideally around the time of diagnosis.

Care planning is reviewed post treatment and at other key points along the care pathway. This involves ensuring that appropriate support networks are in place in clinical and community settings. Improving timely access to support services enables people to return to as normal and healthy lives as soon as possible after treatment (Department of Health, 2004).

Pilot project
NHS Improvement is working with urology teams in four national project sites to test risk-stratified pathways. Within these teams, clinical nurse specialists (CNSs) have a key role in preparing patients, through robust assessment and care planning, in meeting their individual needs and in providing them with the skills to self-manage with support.

The national project sites are: North Bristol Trust; the Hillingdon Hospitals Foundation Trust; the Ipswich Hospital Trust; and Luton and Dunstable Hospital Foundation Trust.

Nurses’ role in PSA monitoring
Prostate cancer often requires lifelong PSA monitoring because it may recur, even if initial treatment was successful. There is no common approach to follow-up after prostate cancer treatment in terms of where and how it takes place, although the timing of tests is more uniform.

Many patients lead normal lives without their condition inhibiting their lifestyle in the longer term and will therefore be suitable, if appropriately prepared, to self-manage.

A monitoring system is needed that is safe, effective and accepted by clinical teams and patients. It should not increase the burden of follow-up and be of minimal inconvenience to patients. Our testing of risk-stratified care has shown that CNSs have an important role in coordinating this monitoring.

Remote monitoring, which provides safe and effective monitoring at a distance with timely intervention if needed, is a crucial support for patients who self-manage. The basic premise is that the system identifies who needs a PSA test at a particular time and generates a letter for the patient and his GP, informing them that the test is due. The patient then has blood taken and it is processed by the laboratory; the results are fed into the remote monitoring system and reviewed by a member of the clinical team, often a CNS. A letter is generated for the patient and his GP notifying them of the result and whether any action needs to be taken.

This system also provides better information for commissioners and service providers on demand for particular services. The remote monitoring system is now going live across the project sites and we hope to report the findings in spring 2013.

Problems after prostate cancer treatment
Patients experience a range of problems following radical treatment for prostate cancer, which can have a significant impact on quality of life. These include:

- Rectal symptoms including bleeding and urgency;
- Urinary symptoms, including incontinence and obstruction;
- Erectile dysfunction;
- Increased risk of other pelvic cancer;
- Bowel toxicity, which can occur following radiotherapy to the prostate or pelvic nodes.

A recent survey by Ipsos MORI (2011) found that 46% of patients with prostate cancer experienced problems with erectile function and, of these, 44% had a problem that remained unresolved. Patients can be further helped and supported through the conversation they have when the issue of erectile problems are raised. Urology specialist nurses are in a unique position to make a positive impact on outcomes for these patients.

Further details on the work at the project sites can be accessed at: tinyurl.com/prostate-survive. For information on NHS Improvement go to: www.improvement.nhs.uk

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