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GPs could play key role in prostate cancer survivorship programmes

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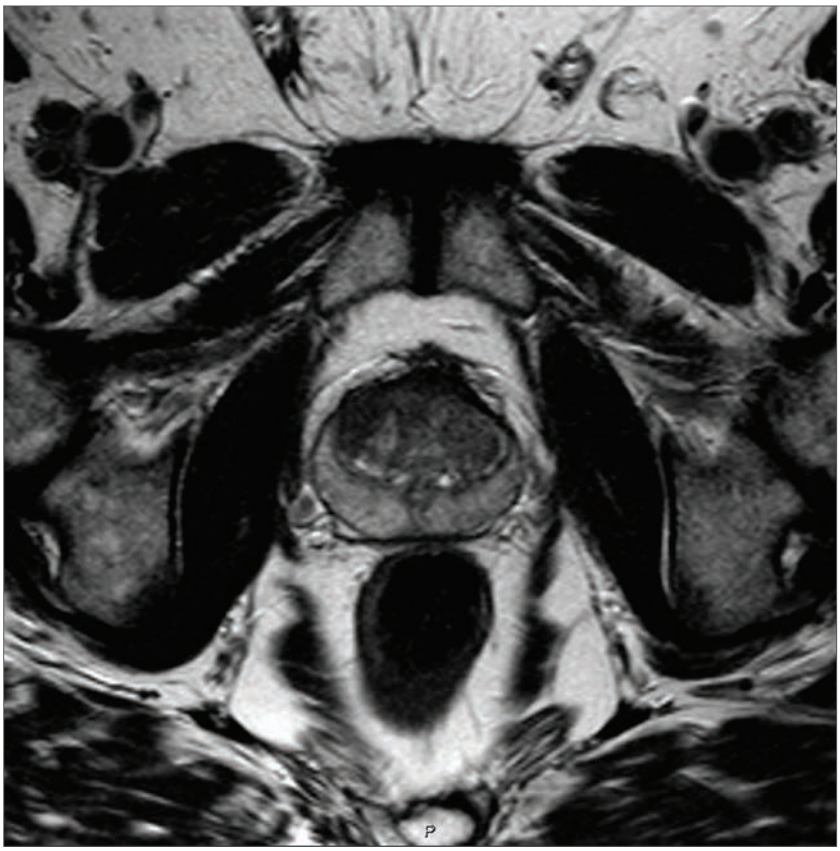


FIGURE 1
Axial MRI prostate demonstrating right peripheral zone prostate cancer

Why are cancer survivorship schemes needed?

What are the essential components?

How will these schemes improve patient care?

PROSTATE CANCER IS THE MOST COMMON MALE CANCER IN THE UK. EARLY DETECTION AND advances in treatment have led to improvements in survival. Today more than 80% of men diagnosed with prostate cancer can expect to survive for at least five years. As a consequence the number of prostate cancer survivors in the UK is rapidly increasing.[1]

Survival alone, however, is no longer a sufficient measure of treatment success. Prostate cancer survivors have unique and evolving needs which are ongoing after treatment. Until recently relatively little attention had been focused on the type of care men with prostate cancer facing long-term survival actually need.

Prostate cancer survivorship is an emerging field of cancer care specifically addressing the phase of care after active treatment. The primary aim is to deliver holistic care to support men with prostate cancer to lead as healthy and active a life for as long as possible. Survivorship begins at diagnosis and extends through to the end of life. The principle underlying prostate cancer survivorship is that follow-up should be tailored to the individual's needs whether oncological, functional or psychological.

PROSTATE CANCER PATHWAY

The accepted path for men with prostate cancer (see figure 1, above) is illustrated in figure 2, p28. Over the past decade several improvements in prostate cancer clinical pathways have been made. Technological advances, centralisation of complex cancer care and the introduction of the multidisciplinary team have helped to reduce geographical inequality and improve oncological outcomes and patient experience.

The introduction of prostate cancer specialist nurses has significantly improved patient experience and has been highly valued by patients. Prostate cancer nurse specialists have been responsible for providing psychological and emotional support, in addition to enhancing the co-ordination of care.[2]

Despite this progress, it is recognised that men often feel abandoned after they have undergone treatment because their ongoing needs, which may not be directly related to treatment, are not addressed.

PATIENTS' UNMET NEEDS

Up to 87% of men with prostate cancer may have unmet supportive care needs.[3] Prostate cancer survivors regularly cite psychological and sexual issues as their most significant unmet supportive care needs.[3,4,5]

In reality these men have a spectrum»

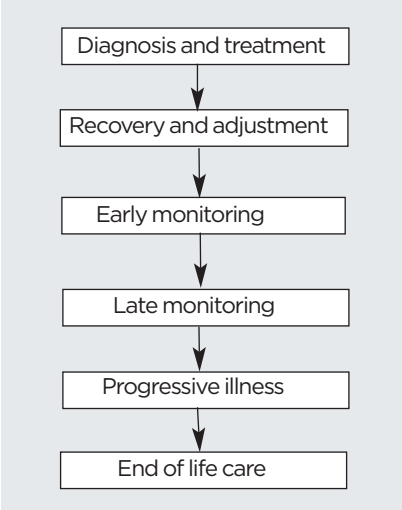


FIGURE 2
The conventional pathway for prostate cancer care

of individual supportive care need ranging from the management of treatment side effects to dealing with financial challenges after a prostate cancer diagnosis.

Poor functional outcomes after treatment such as incontinence and erectile dysfunction are acknowledged to have a major impact on quality of life.[6] Patient preference studies have demonstrated that men with prostate cancer do not feel well informed regarding either their treatment options or their associated side effect profile. There is a need to prepare patients better for their treatment decisions and thus minimise the risk of regret about the choices they make.[7]

Studies have demonstrated that it may be possible to identify patients with increased needs. Psychological distress, especially in relation to emotions and coping, has been demonstrated to be a strong predictor of increased supportive care need throughout the patient's prostate cancer journey.

Uncertainty regarding prostate cancer remission status is also a significant predictor of increased need for information and psychological support.[4] Age, education and marital status may also influence an individual's supportive care needs.[4,8]

SURVIVORSHIP PROGRAMMES

The number of men living with prostate cancer in the UK is predicted to rise from 255,000 to 416,000 in 2020 and 620,000 by 2030. [9] These prostate cancer survivors have differing needs of varying complexity. They are also at risk of developing other chronic conditions related to their cancer treatment or ageing.

The traditional model of hospital follow-up at set intervals after treatment fails to deliver optimum patient-centred cancer care. Hospital appointments tend to be time limited and focus on outcomes related to survival such as the PSA and the functional outcomes of treatment. Holistic aspects of care such as complex psychological needs may go unrecognised or unmanaged during appointments. The opportunity to discuss disease prevention and factors which may facilitate full rehabilitation of patients back into society may also be missed.

'Follow-up should be tailored to the individual's needs whether oncological, functional or psychological'

Secondary care lacks the capacity to manage the predicted rise in prostate cancer survivors alone. In reality, not every man needs intensive hospital follow-up after prostate cancer treatment.

Secondary care follow-up is a resource which should be targeted at patients who require such follow-up. The cost to patients in terms of travelling to hospital appointments, parking, and time off work should also not be forgotten.

There is a need to adapt pathways of care for prostate cancer patients to improve the quality of care and create a more sustainable and integrated service. These challenges have been recognised in the recent NHS England publication NHS Forward View. [10]

Prostate cancer survivorship provides a framework upon which innovative reconfigurations of cancer care can be established to meet the aforementioned challenges.

Survivorship care addresses the physical, psychosocial, mental, functional, spiritual, emotional and practical concerns of daily living.

Survivorship models of care are not one size fits all but place the patient at the centre of the pathway. All patients are risk stratified at diagnosis and at intervals in their pathway to ensure care is tailored to their needs. Men have a clear treatment plan.

Low-risk stable patients may be managed in primary care with a clearly defined route back to secondary care follow-up if there are any concerns. Through this survivors are empowered to return to their pre-treatment status in society. A blurring of the boundaries between secondary and primary care with greater integration is necessary for survivorship to work.

Core components

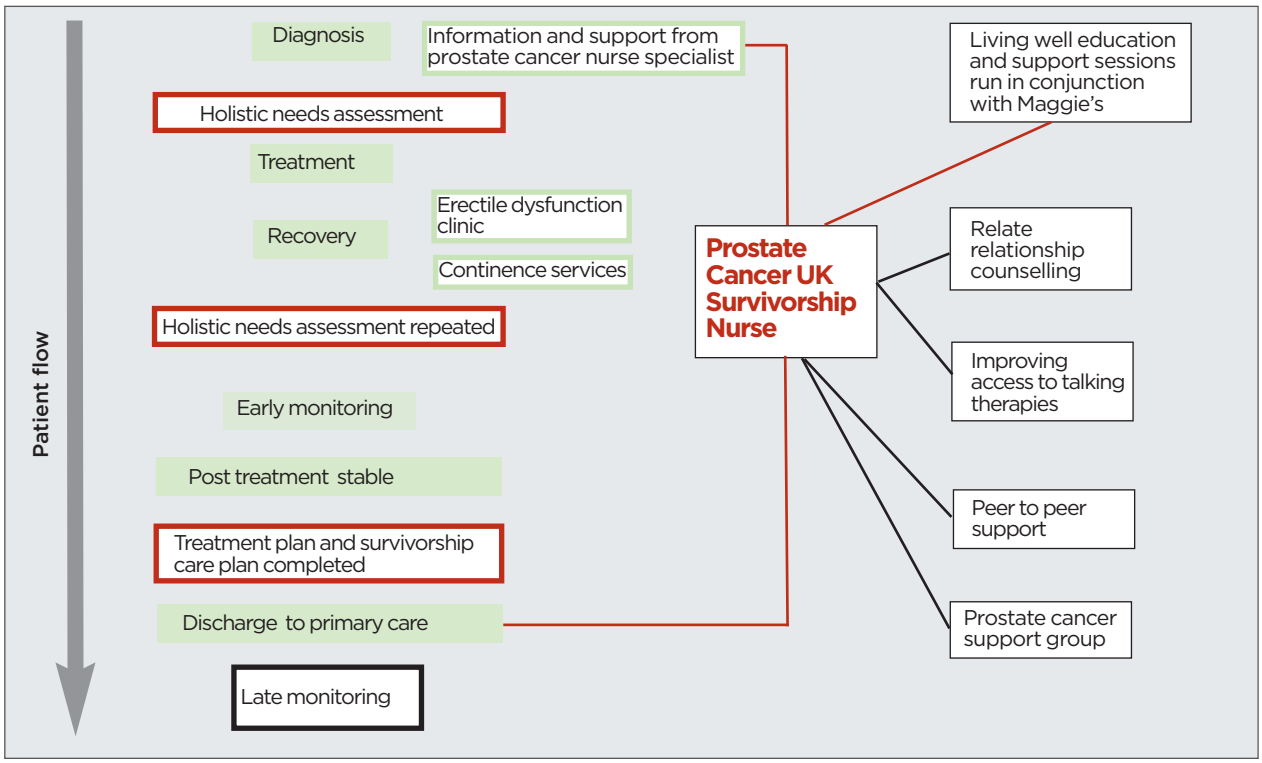
The key elements of a programme are:

- **Education** – about prostate cancer, its treatment, managing treatment side effects and lifestyle after a cancer diagnosis including advice on exercise, nutrition and disease prevention. This may take place on a one-to-one basis in clinic or in a small or large group at an educational event
- **Intervention** – to address psychological and functional treatment-related side effects. This may be provided in appointments with healthcare professionals, for example a continence nurse specialist or psychologist
- **Surveillance** – a risk-stratified shared care approach to monitoring patients for disease recurrence and progression. Low-risk patients may be followed up in primary care. Patients suitable for self-management or remote monitoring would be supported
- **Co-ordination of care** – providing holistic individualised care makes patient pathways more complex. Ideally there should always be at least one person responsible for co-ordinating the programme. This individual has a pivotal role in the pathway: signposting patients to appropriate services and acting as a point of contact and an interface between patients, and primary and secondary care.

'Men often feel abandoned after treatment because their ongoing needs are not addressed'

The National Cancer Survivorship Initiative (NCSI), a partnership between the Department of Health and Macmillan developed a recovery package of key interventions which may improve the immediate care for patients. It includes:

FIGURE 3
The Newcastle prostate cancer survivorship model



- Structured holistic needs assessment and care planning: Face-to-face discussions about the patient's wishes and concerns, held at diagnosis, end of treatment and key points in the pathway. These are documented in a written care plan
- Treatment summaries and cancer care reviews: These contain cancer specific information regarding the patient's tumour characteristics, treatment to date and recommended follow-up plan. These are completed at the end of treatment and copies given to the patient and his GP. These summaries contain information regarding systems to re-access secondary care

'Prostate cancer survivors regularly cite psychological and sexual issues as their most significant unmet supportive care needs'

- Patient education and support events
- Advice about, and access to, physical activity schemes

These interventions enable a shared understanding between patients and professionals about the issues which are important to patients, what to expect during recovery, and identify any needs which need to be addressed. [11]

The recovery package has been piloted successfully in the UK and has been acknowledged to be the minimum standard of care that all cancer patients should be entitled to.[12]

Survivorship programmes across the UK will take various forms depending on local needs and healthcare structures. Case studies from pilot survivorship sites for a variety of tumour groups are available on the NCSI website.[11] The Newcastle model of prostate cancer survivorship is illustrated as an example in figure 3, above.

THE ROLE OF PRIMARY CARE

Whether commissioners or providers of services for their local population, GPs are responsible for ensuring high-quality care for their local population. As such primary care has a major role to play in the adoption and uptake of prostate cancer survivorship.

Best practice guidance issued by the Department of Health to commissioners in 2011 identified survivorship as a priority.[13]

'Men do not feel well informed regarding their treatment options or their associated side effect profile'

GPs are trained and experienced in providing high-quality comprehensive care for patients with complex chronic medical conditions. As such they have the skill set to adopt survivorship principles and support prostate cancer survivors in the community.

For prostate cancer survivorship to be embedded there must be engagement and closer integration between primary and secondary care to build a successful programme. Urologists and GPs need to collaborate to establish shared care pathways for prostate cancer patients.

Key elements of these innovative pathways will include clear follow-up protocols for prostate cancer survivors discharged into the community and rapid access arrangements for patients about whom GPs are concerned.

Many GPs will have had limited »

exposure to urology during their training and may feel uneasy about managing prostate cancer patients in the community.[14] The provision of appropriate education resources and a point of contact to support GPs through this transition is an essential component of a survivorship programme.

In our model, see figure 3, p29, an experienced prostate cancer nurse specialist will co-ordinate the programme and act as an easily accessible interface between patients on the programme, and primary and secondary care.

The nurse specialist through the survivorship programme will also be responsible for preparing patients for discharge into the community. This innovative structure of care will be unfamiliar to patients.

EVIDENCE SUPPORTING SURVIVORSHIP SCHEMES

Prostate cancer survivorship is an emerging research field. In the United States where the majority of survivorship research is performed, only 5% of current survivorship research projects focus on prostate cancer survivors.[15]

The NCSI was established in 2007 and has pioneered developing an evidence base for survivorship in the UK. Establishing a baseline of what current survivorship practice is and the needs of men with prostate cancer in the UK has been a key achievement of the NCSI.[12]

Recent patient survey data estimated that only 24% of cancer survivors across several tumour sites were offered a written needs assessment and care plan.[16] This reflects the fact that survivorship has yet to be widely adopted and therefore evidence from multiple tumour sites must be reflected upon.

Few prospective randomised controlled trials (RCTs) assess the impact on the patient of discharge to primary care for ongoing management and those which do have limitations.

In a study of 408 breast cancer patients who were randomised to either discharge from a clinical oncologist visit directly to primary care or nurse-led discharge with treatment summaries and a survivorship care plan, no significant difference in cancer specific distress was identified after 12 months.[17]

An RCT evaluating oncological providers' experience of a Survivorship Care Plan identified that it was a useful tool. However, 64% of participants had a perceived barrier to using a Survivorship Care Plan. The main concern was not having sufficient time to discuss all the issues.[18]

These studies highlight commonly perceived barriers to the adoption of survivorship. In the UK, 80% of GPs who had received treatment summaries and care plans as part of the NCSI felt they were more informed about their patients' care and 50% felt it improved patient care.[19] This study demonstrates how survivorship can improve communication between primary and secondary care. It also highlights the need for a dedicated role to co-ordinate the programme and complete documentation.

As an NCSI pilot site Worcestershire Acute Health Trust has enrolled 600 patients onto a survivorship programme. Of those patients on the programme only 29 have been reported to require further appointments in secondary care.[20] This reinforces the concept that if patients are appropriately risk stratified they can be safely managed in the community.

Theoretical modelling has demonstrated evidence of a cost benefit resulting from the reduction of secondary care appointments by enroling lung and breast cancer patients in a survivorship programme.[21]

'Survivors are at risk of developing other conditions related to their cancer treatment or ageing'

The American Cancer Society has recently issued guidelines for primary care physicians responsible for managing men with prostate cancer in the community. These provide a comprehensive summary of the evidence base for managing the wide variety of long-term effects survivors may present with.[22]

As the number of survivors rises, future high-quality studies will deliver key information about the benefit of intervention in prostate cancer survivors.

One such UK study which will inform practice is PROSPECTIV a pilot trial of a nurse-led psychoeducational intervention delivered in primary care to prostate cancer survivors.[23]

CONCLUSIONS

The challenge of providing high-quality care to prostate cancer survivors has been recognised and needs to be embraced by both primary and secondary care.

'All patients are risk stratified at diagnosis and at intervals in their pathway so that care is tailored to their needs'

Staying as we are 'will not deliver outcomes, improvements cancer survivors expect, nor will it be affordable to the NHS.'[12] Primary and secondary care working together will enable the development of prostate cancer survivorship models to meet future demand and improve care for prostate cancer patients.

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key points

SELECTED BY
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The number of men living with prostate cancer in the UK is predicted to rise from 255,000 to 416,000 in 2020 and 620,000 by 2030. More than 80% of men diagnosed with prostate cancer can expect to survive for at least five years. Prostate cancer survivors have unique and evolving ongoing needs. Until recently relatively little attention has been focused on the type of care such men actually need.

Up to 87% of men with prostate cancer may have unmet supportive care needs and prostate cancer survivors regularly cite psychological and sexual issues as the most significant. Poor functional outcomes after treatment such as incontinence and erectile dysfunction are acknowledged to have a major impact on quality of life. There is a need to prepare patients better for their treatment decisions and thus minimise the risk of regret about the choices they make.

The traditional model of hospital follow-up at set intervals after treatment fails to deliver optimum patient-centred cancer care. Holistic aspects of care such as complex psychological needs and factors which may facilitate full rehabilitation of patients back into society may be missed.

There is a need to adapt pathways of care for prostate cancer patients to improve the quality of care and create a more sustainable and integrated service. Low-risk stable patients may be managed in primary care with a clearly defined route back to secondary care follow-up if there are any concerns. A blurring of the boundaries between secondary and primary care with greater integration is necessary for survivorship to work.

The key elements of a survivorship programme are: education, intervention, surveillance of survivors and co-ordination of care. Interventions which may improve the immediate care include: structured holistic needs assessment and care planning, treatment summaries and cancer care reviews, patient education and support events and advice about, and access to, physical activity schemes.

Urologists and GPs need to collaborate to establish shared care pathways for prostate cancer patients. Elements of these innovative pathways will include clear follow-up protocols for prostate cancer survivors discharged into the community and rapid access arrangements for patients about whom GPs are concerned.

We welcome your feedback

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Useful information

National Cancer Survivorship Initiative
www.ncsi.org.uk

Macmillan Cancer Support
www.macmillan.org.uk/Aboutus/Healthandsocialcareprofessionals/Macmillansprogrammesandservices/Survivorship.aspx

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