

Debate & Analysis

Cancer survivorship:

the impact on primary care

BACKGROUND

A cancer survivor is defined as a person living with or beyond cancer. There are over 2 million people living in the UK who have been diagnosed with cancer, the majority (1.24 million) were diagnosed more than 5 years ago.¹ As a result of earlier diagnosis and improved treatments, survival rates are increasing and more than 50% of patients will now survive for at least 5 years. Coupled with the growing number of new cases of cancer each year, this means that if current trends continue, the number of cancer survivors will double from 2 million to 4 million in just 20 years. Extrapolation of audit data on patients with cancer in one practice (PWR) suggests that currently in a GP population of 10 000 patients there could be approximately 440 patients overall who have had a diagnosis of cancer (excluding non-melanoma skin cancer) of whom 275 are at least 5 years from diagnosis. The burden on primary care is significant and will continue to increase.

Although survival rates continue to increase, there is no doubt that a diagnosis of cancer can have significant adverse effects (physical, psychological, social, and financial) on both patients and their families (Box 1). Some patients also experience long-term effects of treatment (side effects present during primary curative treatment which persist) or late effects (effects which appear some time — months or even years — after primary treatment has ended).

Box 1. Possible consequences of diagnosis and treatment of cancer

Physical health

- Recurrence
- Immediate side effects of treatment
- Long-term effects of treatment
- Late effects of treatment
- Effect on comorbidities

Psychological health

- Increased depression
- Increased anxiety, including fear of recurrence
- Psychosexual problems
- Quality of life

Social issues

- Financial
- Employment
- Education
- Interpersonal
- Social interaction

Some people will also be living with incurable cancer but are not yet in the last 12 months of life. Primary care is well placed to address these issues and to minimise future ill health for people living with or beyond cancer. However, this will need a change in emphasis to more proactive and structured care. This article will describe the key issues for primary care which emerge during the cancer survivorship phase and will discuss proposals for ways in which pathways of follow-up care could be amended to improve outcomes for patients.

THE CURRENT SITUATION

Currently patients are offered follow-up in hospital for variable lengths of time. Although the purpose of follow-up is rarely discussed with patients, most patients believe it is an important part of their cancer care and derive reassurance from follow-up appointments with cancer specialists.²⁻³

The content of follow-up appointments in hospital is variable but the main focus is usually on detecting recurrence. However, evidence for the efficacy or cost-effectiveness of follow-up in achieving the aim of detecting disease recurrence is equivocal or negative.⁴ For example, comparing the evidence on the effectiveness of more intensive follow-up programmes gives different results for colorectal and breast cancer: more intensive follow-up improves survival⁵⁻⁶ and is cost-effective in colorectal cancer,⁷ whereas in breast cancer there is no advantage in a more intensive regime.⁸ More immediate needs of patients are sometimes not addressed, for example sexual dysfunction or urinary problems,⁹ and these are issues that can significantly affect a patient's quality of life. Some patients report that later follow-up appointments are perfunctory at best, and care is delivered by more junior staff. Patients express some concerns about consulting their GP with cancer-related problems because they do not regard them as experts in this field or they do not want to bother them.¹⁰ Despite these views and the historical lack of formal or structured follow-up by GPs, these patients do consult their GP more often than others of the same age. Patients with breast and colon cancer initially consult their GP once more per year than their peers and consultation rates only converge around 10 years from diagnosis. Men with prostate cancer consult up to three times more per

year and rates do not converge until 15 years from diagnosis.¹¹ The content of these additional appointments is unknown, but at least some will be related to cancer care including general support, discussion of treatment options, undertaking blood tests for monitoring disease, or administering treatments such as tamoxifen and goserelin.

NEW PROPOSALS FOR FOLLOW-UP AFTER TREATMENT

The increased numbers of patients with cancer, the emphasis on earlier and more expeditious diagnosis, and the acknowledgement that there are many important aspects of follow-up in addition to detection of recurrence have resulted in proposals to change the way follow-up care is delivered. Patients with cancer are a high-risk cohort for medical morbidity, not only because of the possible relapse of their cancer and the treatments that they have undergone, but also because the risk factors for their cancer may also be risk factors for other diseases. GP records will document these risk factors and this is an argument for a structured follow-up of these patients in the long term.

It is proposed that, in future, patients will undergo risk stratification according to risk of recurrence, long-term effects, and other medical, practical, or emotional conditions, and be placed into three categories.¹² The majority will be in the low-risk category and these patients will be supported to self-manage their condition in the manner of those with other long-term conditions, such as diabetes or heart disease, with open access to secondary care services if required. For example, an assessment of need will be carried out and a care plan then produced in partnership with the patient. This should give patients realistic expectations about the purpose of follow-up and the need for a multiprofessional approach including GPs. Some will be offered the opportunity to attend an education event, health and wellbeing clinic, or self-management programme. Patients will be assigned a key worker and easy access back to the hospital system if there are problems. If this plan is implemented there will be more patients having follow-up in the community and this is likely to mean a wider role for GPs in this area. Those in moderate and high-risk categories will continue to be offered shared care

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[moderate risk] or complex case management in hospitals through a multidisciplinary team (high risk).

IMPLICATIONS FOR PRIMARY CARE

What are the implications of these proposed changes for those working in primary care? First, this must not be seen as a plan to ‘dump’ cancer follow-up on primary care. GPs are already seeing these people and managing some aspects of their care, both for their cancer (for example, melanoma follow-up, PSA monitoring) and their comorbidities. GPs are well placed to deliver this because they offer care covering physical, psychological, and social aspects of medicine, are experts at delivering longitudinal chronic disease management, and already manage the comorbidities and psychological problems of these people (although psychological problems often go undetected and more could be done).

Evidence suggests that comorbidities and prevention and screening are already well managed by GPs in cancer compared with non-cancer patients.^{13–14} Primary care can also support the families of these people and are familiar with signposting to other agencies. However, studies with patients have indicated they would welcome greater acknowledgement from their GP regarding their diagnosis and treatments and more general support from the practice;¹⁰ these issues would be addressed by more formalised care.

Cancer care reviews have been introduced to help GPs engage with their cancer patients within 6 months of diagnosis. However, there are some deficiencies in the current system and it has been suggested that cancer care reviews should be proactive and more structured.¹⁰ Macmillan Cancer Support has worked with the major IT providers to develop electronic templates of subjects to cover in the review. It enables GPs to signpost people to relevant support, such as benefits advice; 88% of GPs found it useful for identifying resources the patient may need; for example, to enable the patient to return to work.¹⁵ The current timing of the single review does not cover both treatment decisions and end-of-treatment issues. The

transition from hospital follow-up to primary care management is another important time where an additional appointment with the GP, for those who wish it, could enable planning of the next stage of surveillance.

The development of individualised holistic needs assessment and Survivorship Care Plans (SCP), which are agreed with the patient, will summarise diagnosis, treatment, and ongoing management requirements, highlight symptoms which warrant referral back, and support GPs in less familiar areas, such as the late effects of treatment, including risks of second cancers.¹⁶ SCPs are currently being trialled in the UK in a number of pilot sites around the country and, if successful, are likely to be implemented.¹⁷ Treatment summaries, which form one part of the SCP, have been evaluated by National Cancer Survivorship Initiative/Macmillan Cancer Support, and although they pose workload implications for oncologists, they have been well received by both primary and secondary care. They are acknowledged as a concise and useful communication tool and there is a determination to continue to produce these documents in the areas where they have been piloted. Testing identified that 80% of GPs found the treatment summary useful or very useful and 90% wanted the service to continue; 50% of GPs felt it would improve the care they gave.¹⁸

Practice nurses are playing an increasingly important role in the management of many chronic diseases and there is no reason why cancer should be an exception. Macmillan Cancer Support has surveyed nurses views about involvement in cancer follow-up and many expressed a lack of confidence in dealing with cancer patients. A pilot project has been set up by Macmillan Cancer Support to develop the role of practice nurses in this area and addresses their lack of confidence by building on the well developed and interchangeable skills already gained in other areas of chronic disease management.

New management systems will need to be developed to facilitate greater involvement of primary care in cancer

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follow-up. Patient records will need to be coded to ensure that they can be identified for screening and prevention measures. More rigorous recall systems will also be necessary to ensure monitoring is efficiently carried out. Simple recall systems can easily be introduced using a single Read code (for example 8AZ) for recall linked to a database defining what procedure the recall indicates. Alternatively, recall systems could be centralised. Lastly, the enhanced commissioning role for primary care should ensure that there is a whole systems approach to supporting survivors.

CONCLUSION

The increasing number of survivors inevitably means an enhanced role for primary care in providing follow-up care. The deficiencies of the current system in primary and secondary care are well documented and the proposed changes will address these and ensure improved care which is focused on the needs of patients. Evaluation of any changes will be needed to ensure they are effective. Primary care must start preparing for these changes now because there are both educational implications for individual GPs and management implications for practices.

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REFERENCES

1. Maddams J, Brewster D, Gavin A, *et al*. Cancer prevalence in the United Kingdom: estimates for 2008. *Br J Cancer* 2009; **101(3)**: 541–547.
2. Lewis RA, Neal RD, Hendry M, *et al*. Patients' and health care professionals' views of cancer follow-up: systematic review. *Br J Gen Pract* 2009; **59(564)**: 533–540.
3. Frew G, Smith A, Zutshi B, *et al*. Results of a quantitative survey to explore both perceptions of the purposes of follow-up and preferences for methods of follow-up delivery among service users, primary care practitioners and specialist clinicians after cancer treatment. *Clin Oncol (R Coll Radiol)* 2010; **22(10)**: 874–884.
4. Corner J. Addressing the needs of cancer survivors: issues and challenges. *Expert Rev Pharmacoecon Outcomes Res* 2008; **8(5)**: 443–451.
5. Jeffery M, Hickey BE, Hider PN. Follow-up strategies for patients treated for non-metastatic colorectal cancer. *Cochrane Database Syst Rev* 2007; **(1)**: CD002200.
6. Renehan AG, Egger M, Saunders MP, O'Dwyer ST. Impact on survival of intensive follow up after curative resection for colorectal cancer: systematic review and meta-analysis of randomised trials. *BMJ* 2002; **324(7341)**: 813.
7. Renehan AG, O'Dwyer ST, Whynes DK. Cost effectiveness analysis of intensive versus conventional follow up after curative resection for colorectal cancer. *BMJ* 2004; **328(7431)**: 81.
8. Rojas MP, Telaro E, Russo A, *et al*. Follow-up strategies for women treated for early breast cancer. *Cochrane Database Syst Rev* 2000; **(4)**: CD001768.
9. O'Brien R, Rose PW, Campbell C, *et al*. Experiences of follow-up after treatment in patients with prostate cancer: a qualitative study. *BJU Int* 2010; **106(7)**: 998–1003.
10. Adams E, Boulton M, Rose P, *et al*. Views of cancer care reviews in primary care: a qualitative study. *Br J Gen Pract* 2011; DOI: 10.3399/bjgp11X567108.
11. Khan NF, Watson E, Rose PW. Primary care consultation behaviours of long-term, adult survivors of cancer in the UK. *Br J Gen Pract* 2011; DOI: 10.3399/bjgp11X561195.
12. NHS Improvement. *Effective follow up: testing risk stratified pathways*. Leicester: NHS Improvement, 2011. <http://www.ncsi.org.uk/wp-content/uploads/RiskStratifiedPathways-May-2011.pdf> [accessed 22 Sep 2011].
13. Khan NF, Mant D, Rose PW. Quality of care for chronic diseases in a British cohort of long-term cancer survivors. *Ann Fam Med* 2010; **8(5)**: 418–424.
14. Khan NF, Carpenter L, Watson E, Rose PW. Cancer screening and preventative care among long-term cancer survivors in the United Kingdom. *Br J Cancer* 2010; **102(7)**: 1085–1090.
15. Torjesen I. Forward planning. HSJ: Cancer survivorship. *HSJ Supplement* 14 April 2011; 1–14. http://www.ncsi.org.uk/wp-content/uploads/HSJ_survivorship_supplement.pdf [accessed 22 Sep 2011].
16. Gilbert SM, Miller DC, Hollenbeck BK, *et al*. Cancer survivorship: challenges and changing paradigms. *J Urol* 2008; **179(2)**: 431–438.
17. National Cancer Survivorship Initiative. *Test communities*. London: MacMillan Cancer Support, 2011. <http://www.ncsi.org.uk/test-communities> [accessed 22 Sep 2011].
18. National Cancer Survivorship Initiative. *Treatment summary*. London: MacMillan Cancer Support, 2011. <http://www.ncsi.org.uk/what-we-are-doing/assessment-care-planning/treatment-summary/> [accessed 22 Sep 2011].