Cancer survivorship: living with or beyond cancer


Abstract
An estimated two million people in the UK are living with or beyond cancer – they are cancer ‘survivors’. The disease is no longer a death sentence but a chronic condition for many people. As a result, many people are living with the long-term physical and psychosocial implications of cancer and its treatment. Nurses play a pivotal role in providing advice, guidance, education and support to cancer survivors. They help develop and implement new ways of working, including extended patient follow up, more ambulatory care and greater patient/provider partnership interactions. This not only helps to enhance the support available to survivors, but also provides opportunities for specialist nurses to use and develop their clinical and interpersonal skills.

Aims and intended learning outcomes
This article aims to explore the implications for specialist nursing and service delivery of the increase in cancer survivorship in the UK. Government initiatives designed to improve the care and support available to survivors are also discussed, as well as the nurse’s role in enhancing the quality of support available to survivors. After reading this article, you should be able to:

■ Define cancer survivorship.
■ List government policies and initiatives in the field of survivorship.
■ Summarise service delivery developments currently under way.
■ Summarise your role in supporting cancer survivors.
■ Identify the clinical and interpersonal skills required to support cancer survivors.

Introduction
In England, 242,200 new cases of malignant cancer, excluding non-melanoma skin cancer, were registered in 2006, 121,600 of which were in men and 120,600 in women (Office for National Statistics (ONS) 2008). The four most common cancers – breast, lung, colorectal and prostate cancer – accounted for more than half of all new cases (ONS 2008). Cancer is a leading cause of mortality worldwide and 2007 saw 7.9 million cancer-related deaths (about 1.3 per cent of all deaths) (World Health Organization 2009).

While the incidence of cancer is on the increase, so are survival rates. In England, the three-year average death rates for cancer (ages under 75) fell by 18.2 per cent between 1993 and 2007 (Department of Health (DH) 2008). Earlier detection and more efficacious treatments have led to an increase in survival. Overall, it is estimated that there are now two million cancer survivors in the UK, which equates to about 3.3 per cent of the population (Maddams et al 2008). This figure is rising at an estimated 3.2 per cent a year, with breast cancer contributing the most to this total. Indeed, an estimated 550,000 women currently alive have had a diagnosis of breast cancer (Maddams et al 2008).

‘Survivorship’ has been defined by Macmillan Cancer Support (2008) as ‘living with or beyond cancer’. The definition encompasses people who have completed initial cancer management and have no active disease,
Implications of long-term treatment

As an example of long-term treatment implications, reflect on the process of chemotherapy:

- Cytotoxic chemicals are administered into the body.
- Anthracyclines, cytotoxic drugs with antibiotic properties, although among the most effective chemotherapeutic agents (Minotti et al. 2007), are known to be cardiotoxic (damage heart muscle).
- Chemotherapy reduces the body’s ability to fight infection.

In this case, what do terms such as recovery and rehabilitation mean? In your experience, is this a matter of discovering and learning to work with new limits?

The following video will facilitate completion of this exercise: www.ehow.com/video_4872385_long-term-side-effects-from-chemotherapy.html (Last accessed: August 14 2009.)

people living with progressive (but not terminal) disease may be undergoing treatment for cancer, and people who have had cancer in the past.

An increase in survivorship is certainly a magnificent feat for the healthcare system, but it is not without personal and economic implications. As cancer patients live longer, research has documented that many survivors experience significant negative effects from the disease and/or its treatment on the quality of their daily lives. These negative effects can appear and persist long after the completion of treatment (Ferrell et al. 1995, Gotay and Muraoka 1998, Hewitt et al. 2003).

Treatment implications

Depending on the type of cancer, treatment and individual circumstances, survivors can experience a multitude of post-treatment effects (Welch-McCaffrey et al. 1989).

Physically, survivors might develop other illnesses as a result of treatment, such as heart disease, renal impairment, hypertension, osteoporosis, sexual impairment (Dubbelman et al. 2006), early menopause (Ganz 2005) or infertility (Ganz 1998, Maduro et al. 2003, Penson et al. 2003, Kim 2006). Furthermore, treatments can result in adverse physical complaints such as pain, chronic fatigue (Loge et al. 2000), cognitive impairments (Tannock et al. 2004) and lymphoedema. Psychologically, cancer survivors commonly experience fear of recurrence (Lee-Jones et al. 1997), anxiety associated with discharge from hospital (Thomas et al. 1997), clinical depression (Massie 2004) and uncertainties about the future (Holland and Reznik 2005). Social implications include being unable to return to work (Short et al. 2005, 2007) and reduced social integration (Schag et al. 1994).

Now do Time out 2.

Despite this array of implications for quality of life, many survivors report personal growth and positive lifestyle changes (Thornton 2002, Weiss 2004). Research by Pemberger et al. (2005) has, in fact, found that cancer survivors are more likely than the general population to have a positive outlook on life. When confronted with their mortality, people sometimes re-evaluate or change their goals and priorities, thus developing a greater appreciation of life (Tedeschi and Calhoun 1995, Antoni et al. 2 001). This has been referred to as ‘benefit finding’ and is a common experience in cancer survivors (Andrykowski and Hunt 1993, Cordova et al. 2001).

Cancer nurse specialists

The Cancer Reform Strategy (DH 2007) outlined the need for a National Cancer Survivorship Initiative to improve the ongoing support available to survivors. This was based on the premise that survivors may need different kinds of care and support from those traditionally available to cancer patients. Initiatives proposed to improve patients’ experience of living with and beyond cancer include a focus on eight key areas (Box 1).

Recognition of the vital role that the clinical nurse specialist (CNS) can play in improving the experience of cancer survivors is perhaps one of the most decisive areas cited in the Cancer Reform Strategy. The traditional role of nurses with specialist expertise in cancer has been to co-ordinate and support the patient from the point of diagnosis to the completion of treatment. However, these skills can play a valuable role across many different elements of management and support for survivors. The role of the CNS in providing effective psychological support has been emphasised (DH 2007) in particular.

The CNS, and indeed all nurses working with cancer survivors, can provide emotional support to patients as they make sense of their experience, re-evaluate their priorities in life and set goals for healthy living and social reintegration. However, nurses can sometimes be poor at recognising psychological distress (Nichols 2003, Ridner 2004), leading to the emphasis on training in communication and the need for making psychological support an integral and automatic component of models of care.

Now do Time out 3.

Box 1 Eight key areas of survivorship improvement

- Information, communication, decision making and choice.
- Co-ordination and continuity of care.
- Psychological support.
- Supportive and palliative care.
- Appropriate training for healthcare professionals.
- Helping patients to meet the cost of cancer.
- Measuring patients’ experiences as a mechanism for improving the quality of services.
- The critical importance of clinical nurse specialists.

(Department of Health 2007)
Continuing professional development and responding to the needs of cancer survivors. The as part of an integrated disciplinary team will be needed. Training in effective delivery of information and working dealing with the needs of survivors. Even then, further especially as the CNS has the most appropriate skills for in future. This is concerning for several reasons, gastrointestinal cancers may potentially lead to problems to support patients with urological, lung and upper Cancer Charter for Action 2007). The number of CNSs has greatly increased over the past decade. However, for certain types of cancer, upwards of 20 per cent of multidisciplinary teams do not have CNS cover. These include some lung, urology, gynaecology and upper gastroenterology teams. Data indicate that there is still great variation across cancer networks in the number of CNSs available to support patients (Prostate Cancer Charter for Action 2007).

A report by the Prostate Cancer Charter for Action identified significant differences in provision of CNSs in relation to different tumours, resulting in considerable variation in the average caseload handled by each CNS (Prostate Cancer Charter for Action 2007). For example, breast cancer and gynaecology nurse specialists have the lowest average caseloads, with 78 patients per whole-time-equivalent CNS. Lung cancer and urology nurse specialists have the highest average caseloads at 123 and 132 patients per whole-time-equivalent nurse, respectively (Prostate Cancer Charter for Action 2007).

These shortfalls in the number of CNSs available to support patients with urological, lung and upper gastrointestinal cancers may potentially lead to problems in future. This is concerning for several reasons, especially as the CNS has the most appropriate skills for dealing with the needs of survivors. Even then, further training in effective delivery of information and working as part of an integrated disciplinary team will be needed.

The same is true of skills in assessing, managing and responding to the needs of cancer survivors. The Advanced Communications Skills Training programme is fully developed and has been implemented across cancer networks. The course is now known as Connected, the national communication skills training programme, and continuing professional development credits are available to nurses who attend.

Now do Time out 4.

Time out

Reflect on, and discuss, with a colleague your role in the following areas of management and support for cancer survivors:

- Technical, such as treatment delivery or the development of post-treatment care plans.
- Informational, for example communication, signposting to relevant support services.
- Emotional.
- Co-ordination.

Did you cover all the functions listed in Box 2?

Box 2 The nurse's role in management and support

- Familial risk assessment.
- Communication and information.
- Delivering treatment, such as chemotherapy.
- Psychological and emotional support for patients and families.
- Providing continuity of care.
- Supporting and advising patients' families and carers.
- Developing a post-treatment plan.

The same is true of skills in assessing, managing and responding to the needs of cancer survivors. The

Box 3 The seven work streams of the national survivorship scheme

- Assessment, care planning and immediate post-treatment approaches to care. Example: the development and testing of a standardised model of post-treatment follow-up care that would enable equality and consistency in the delivery of survivorship care.
- Managing active, progressive and recurrent disease. Example: creating a responsive service that takes into account the individual health needs of survivors and carers.
- Survivors of childhood cancers. For example: work towards ensuring that young cancer survivors have equal opportunities for educational achievement.
- Research. Example: a review of the current literature on survivorship in order to devise a future research agenda.

National initiative

In general, survivorship initiatives are in their infancy. Indeed, as recently as September 2008, the National Cancer Survivorship Initiative (NCSI) was established to support the survivorship agenda. The NCSI is co-chaired by Ciarán Devane, chief executive of Macmillan Cancer Support, and Mike Richards, national cancer director, with a steering group overseeing the delivery of the agenda. Work streams have been established in seven areas of survivorship (Box 3).

The goal of each work stream is described below, along with examples of activities being carried out by each. Some speculation about the future outcomes of these work streams, especially in regard to nursing, will be discussed. Once the work of the individual streams is more advanced, cross-cutting groups will be established.

The plan is for the work streams to have reached initial

Time out

Take some time to investigate Connected (www.connected.nhs.uk):

- What does the course offer?
- Could you benefit from the course?
- If you feel the course would be useful, discuss this with a supervisor.
- Make your colleagues aware of this training programme.

Advanced Communications Skills Training programme is fully developed and has been implemented across cancer networks. The course is now known as Connected, the national communication skills training programme, and continuing professional development credits are available to nurses who attend.

Now do Time out 4.
Continuing professional development

conclusions in time for a vision and implementation plan to be published this autumn.

The NCSI has identified 16 test communities to map their adult survivorship pathway, identify opportunities for improvement and pilot these in communities, to establish people’s experiences and needs and suggest focuses of work in the streams identified in Box 3. NHS Improvement is overseeing and managing this process across the seven work streams.

**Work stream 1: Assessment, care planning and immediate post-treatment approaches to care** While there are clear treatment and palliative care pathways, there is also recognition of the need for a survivorship care pathway (Shuttleworth 2009). As with many long-term conditions, nurses will have the opportunity to play an important role in this pathway. Their input is likely to be sought in developing an assessment and care planning framework to ensure appropriate and holistic assessment of post-treatment care, and that there is clarity on its delivery. Furthermore, once a survivorship pathway is established, nurses are likely to be involved in the emerging survivorship group programmes.

One such programme is ‘Moving on with Confidence’ at Buckinghamshire Hospitals NHS Trust, a six-week Macmillan-sponsored course for people who have finished active cancer treatment (Shuttleworth 2009). It aims to enhance coping skills and wellbeing. Each two-hour session covers a range of subjects to help group members identify their responses to stress and provide them with practical and emotional coping strategies. Administering treatment and providing psychological support in acute settings will no longer be the primary role of nurses, as longer term follow up and ambulatory care become fundamental to a holistic care pathway.

Now do Time out 5.

**Work stream 2: Managing active, progressive and recurrent disease** A significant proportion of people with active cancer survive long term and have a wide spectrum of needs. Specialist follow-up care, rapid access to appropriate services when patients need them, psychological support for the patient and carer(s), concordance with treatment, relationships with multidisciplinary treatment teams, support with comorbidities and a focus on holistic quality of life are matters of fundamental importance identified by the second NCSI work stream.

Nurses are likely to be supporting patients in developing the coping skills needed to deal with a progressive or recurrent disease and any subsequent emotional exhaustion encountered. They are also likely to be involved in educating survivors on risk management, the detection of recurrence and the availability of specialist services for specific needs, such as psychological support and advice on symptoms. A key aim is to move follow-up care closer to home, so nurses may be required to provide more care in the community.

**Work stream 3: Late effects of treatment** As highlighted in the introduction, survivors of cancer are likely to experience treatment-related health problems many years after treatment has finished. For this reason, late-effects treatment programmes have been developed; these are often facilitated by specialist nurses such as lymphoma nurses. The focus of work is often to manage or limit the effects of treatment, helping patients to secure and protect their remaining physiological function. Nurses are likely to be engaged to a much greater degree in health promotion activities, advising on health and lifestyle factors that can help reduce or control the late effects of treatment. Macmillan Cancer Support (2009) has been developing toolkits to help health professionals to communicate about difficult subjects, such as the long-term sexual implications of many cancer treatments.

**Work stream 4: Survivors of childhood cancers** More than 20,000 survivors of childhood cancer live in the UK (Macmillan Cancer Support 2008). Their needs are specific in terms of absence from school and subsequent reduced opportunities for education and employment. Further potential implications include growth and development problems resulting from treatment and the late physical and emotional effects of cancer that can continue into adulthood.

In many paediatric oncology units, nurses already provide much of the care delivered to children in a community setting and are therefore often best placed to co-ordinate the wider aspects of care. This care is likely to expand to involvement in the testing of various models of care, as well as input into the development of a national guidance framework for schools, pupils, patients and parents of cancer survivors to support re-entry into education and employment. A greater emphasis on multidisciplinary work is therefore likely when new models of care for child survivors of cancer are devised and tested. Nurses might be partnered with schools and employment services in attempts to establish the core needs of this special group.

---

**Time out 5**

**The patient pathway**

Reflect on a recent care plan or pathway you have developed or contributed to:

- How do you consider such pathways might vary between patients in active treatment and survivors?
- Talk to one patient in active treatment and one survivor to help you inform your analysis.
- Share new insights with a colleague.
Work stream 5: Work and finance  In the UK, more than three quarters of a million people of working age are survivors of cancer (Macmillan Cancer Support 2008), with about 62 per cent of those diagnosed with the disease estimated to be able to return to work (Spelten et al 2002). Nevertheless, one survey found that fewer than half the respondents were given advice on the effects treatment might have on their work (Morrell 2005). This lack of guidance affects other financial aspects of people’s lives. Macmillan Cancer Relief (2004) found that as many as 54 per cent of people who died from cancer did not receive disability living allowance or attendance allowance, to which they were entitled.

This work stream is developing models of vocational rehabilitation for testing, as well as triage tools on work and finance to support care planning and guidelines on providing advice. Although nurses may not always be the most appropriate people to carry out assessments in this area of care, they are likely to be involved in the pilot testing of such initiatives, as well as in providing vocational and financial information. Their role may involve identifying needs and referring survivors to other services, such as vocational rehabilitation advisers.

Work stream 6: Self-management  Self-management is becoming increasingly important in reducing the burden of chronic disease on the patient and health services. Several self-management programmes have been developed, with some designed specifically for cancer survivors. The ‘Living with Cancer’ self-management programme delivered by the Mustard Tree Macmillan Service in Plymouth Hospitals NHS Trust is led by a nurse consultant in cancer rehabilitation. Macmillan Cancer Support also provides a ‘Living with Cancer Programme’, which is a free six-week course delivered across the UK. Facilitated by trained tutors who have had cancer, meetings are held each week for learning new self-management skills and techniques.

Nurses are involved in delivering or co-ordinating some of these new programmes, and they also play a pivotal role in educating survivors about self-management and the programmes available.

Research by the Health Foundation (2008) shows that improvements in healthy behaviours are generally not sustained by patients unless health professionals are skilled in providing self-management support. To support professionals to develop appropriate attitudes and behaviours that would facilitate self-management, Skills for Care and Skills for Health (2008) has agreed a common set of core principles for staff development. As a result, nurses and other healthcare providers will be taught goal setting and motivational interviewing techniques to enhance their skills in working in partnership with cancer survivors. Nurses’ efforts will move away from a focus on people who are ill towards a more holistic model of care that encapsulates achieving and maintaining long-term health goals.

Work stream 7: Research  Nurses are central to the achievement of higher standards of care, the delivery of best outcomes and high-quality experience for patients and families. This can be achieved only if nurses actively engage in research and disseminate the results. Despite some progress (Soanes et al 2003), much remains to be done to maximise the nursing contribution to research and development. In particular, nursing research should play a leading role in understanding and optimising how symptoms are best managed by survivors (Ruccione et al 2005). A research agenda for cancer survivorship (Ayanian and Jacobsen 2006) recommends that research should focus on improving quality of life for cancer survivors, with endpoints other than survival and disease-free survival, and identifying risk factors for developing long-term problems as a cancer survivor.

Implications for nursing  Survivorship initiatives offer a new way of working for most nurses, and training will be needed to deliver a survivorship care pathway. This training will enable nurses to develop the skills to raise difficult subjects such as psychosexual or relationship problems sensitively so that patients feel able to discuss them. Such training will also enable nurses to recognise when they can support patients themselves and when to refer them elsewhere for more specialist input.

Cancer is a chronic condition, as are some of the long-term adverse effects carried into survivorship.

Box 4 Department of Health guidance on chronic conditions

Continuing professional development

Nurses thus need to make themselves aware of several important DH documents (Box 4). These documents all place emphasis on people with chronic conditions wanting to be more involved in the self-management of their condition. People want to know about appropriate diet and lifestyle changes, how to manage the effects of treatment, and where more support is available if they need it (Wilson 2008).

Conclusion

The personal and economic burdens of surviving cancer are vast. Advances in detection and treatment of cancer, along with the subsequent increase in the number of people surviving cancer, have resulted in the recognition of a new patient group. Government initiatives are in place to enhance the quality of care available to survivors.

References


Nurses play a central role in the follow up and support of people living with and beyond cancer. This will involve a new way of working for many nurses, moving the focus away from acute care in hospitals to ambulatory follow up and holistic support. This will offer new challenges, as well as opportunities to use an array of clinical and interpersonal skills.
Practice profile

What do I do now?
- Using the information in section 1 to guide you, write a practice profile of between 750 and 1,000 words – ensuring that you have related it to the article that you have studied. See the examples in section 2.
- Write ‘Practice Profile’ at the top of your entry followed by your name, the title of the article, which is: ‘Cancer survivorship: living with or beyond cancer’, and the article number, which is CN267.
- Complete all of the requirements of the cut-out form provided and attach it securely to your practice profile. Failure to do so will mean that your practice profile cannot be considered for a certificate.
- You are entitled to unlimited free entries.
- Using an A4 envelope, send for your free assessment to: Practice Profile, RCN Publishing Company, Freepost PAM 10155, Harrow, Middlesex HA1 3BR by September 2010. Please do not staple your practice profile and cut-out slip – paper-clips are recommended. You can also email practice profiles to practiceprofile@rcnpublishing.co.uk. You must also provide the same information that is requested on the cut-out form. Type ‘Practice Profile’ in the email subject field to ensure you are sent a response confirming receipt.
- You will be informed in writing of your result. A certificate is awarded for successful completion of the practice profile.

1. Framework for reflection
- Study the checklist (section 3).
- What have I learnt from this article?
- To what extent were the intended learning outcomes met?
- What do I know, or can I do, now, that I did not/could not before reading the article?
- What can I apply immediately to my practice or client/patient care?
- Is there anything that I did not understand, need to explore or read about further, to clarify my understanding?
- What else do I need to do/know to extend my professional development in this area?
- How might I achieve the above needs? (It might be helpful to convert these to short/medium/long-term goals and draw up an action plan.)

2. Examples of practice profile entries
- Example 1 After reading a CPD article on ‘Communication skills’, Jenny, a practice nurse, reflects on her own communication skills and re-arranges her clinic room so that she will sit next to patients when talking to them. She makes a conscious decision to pay attention to her own body language, posture and eye contact, and notices that communication with patients improves. This forms the basis of her practice profile.
- Example 2 After reading a CPD article on ‘Wound care’, Amajit, a senior staff nurse on a surgical ward, approached the nurse manager about her concerns about wound infections on the ward. Following an audit that Amajit undertook, a protocol for dressing wounds was established which led to a reduction in wound infections in her ward and across the directorate. Amajit used this experience for her practice profile and is now taking part in a region-wide research project.

3. Portfolio submission
Checklist for submitting your practice profile:
- Have you related your practice profile to the article?
- Have you headed your entry with: the title ‘Practice Profile’; your name; the title of the article; and the article number?
- Have you written between 750 and 1,000 words?
- Have you kept a copy of the practice profile for your own portfolio?
- Have you completed the cut-out form and attached it to your entry?