Cancer survivorship 1: how services need to change for those living with and beyond cancer

As cancer treatments and supportive approaches lead to more people living with and beyond a cancer diagnosis, what are the implications for care and services?

HISTORICAL CONTEXT
Surviving childhood cancer is not a new phenomenon – the widespread introduction of chemotherapy in the 1960s led to early successes. In the 1970s, the multidisciplinary approach and the monitoring of practice through the United Kingdom Childhood Cancer Study Group led to improvements in the five-year survival rates for both leukaemia and solid tumours (Curry et al, 2006).

In adults, the first significant changes in survival rates occurred with the development of cancer services following the Policy Framework for Commissioning Cancer Services (Department of Health, 1995). This report was drawn up after differences in survival rates across the country were identified, which had led to questions about individual practice, hospital performance, service availability and the “postcode lottery”.

It had also been identified that survival rates in the UK were poor compared with other countries. These poor UK rates were often blamed on late presentation and poor early detection rates, despite world class screening programmes such as that for cervical cancer. The data showed that most countries across Europe and most developed countries had better survival rates than the UK.

The government responded with the NHS cancer plan (DH, 2000), which set out a national framework for developing and delivering cancer services.

IMPROVEMENTS IN SURVIVAL
By the mid-1990s, changes in service provision and treatments, such as a planned and coordinated approach in surgery, radiotherapy and combination chemotherapy, led to a steady increase in five-year survival rates and a decrease in mortality in adult cancers in the UK (National Audit Office, 2004).

LEARNING OBJECTIVES
● Understand the potential implications of surviving cancer.
● Be aware of the support services that may need to be developed to manage this client group.

Worldwide survival rates were also improving during this time. A US report said that around 62% of cancer survivors were expected to live at least five years after diagnosis (Centers for Disease Control and Prevention and the Lance Armstrong Foundation, 2004). It also reported that in January 2000 there were around 9.6 million cancer survivors in the US.

The DH (2007) cancer reform strategy aimed to build on the NHS cancer plan and ensure direction in service development until 2012, particularly in areas such as early detection and radiotherapy provision.

Research by Macmillan Cancer Support (2008a) showed an estimated two million people living with or beyond cancer in the UK, nearly double the previous estimate of 1.2 million from research published in 2003. The findings also revealed that 61% of people with a cancer diagnosis are over 65, and 10% of people in the UK aged over 65 have a cancer diagnosis. The reasons for this increase include the fact that people are living longer, meaning that cancer incidence is increasing, as well as improvements in healthcare and decreasing mortality rates.

Cancer Research UK (2009) has reported that survival rates for breast cancer have been improving for 30 years. The most recent figures for women diagnosed with breast cancer in England in 2001-06 showed five-year relative survival to be 82%, compared with 52% 30 years ago. The estimated relative 20-year survival rate increased from 44% in the early 1990s to 64%.

CONSEQUENCES OF SURVIVAL
While people with cancer are surviving for longer and five-year survival rates are increasing, there are long-term consequences for many survivors.

The three modalities used to treat cancer...
– chemotherapy, radiotherapy and surgery – all have physical and psychological effects. Surgery may be disfiguring or require the removal of an organ, and chemotherapy can cause damage to physiological processes such as hormone production.

While modern radiotherapy protocols minimise damage to healthy tissue, this treatment damages any healthy tissue with which it does come into contact, leading to possible DNA damage and the possibility of secondary tumours. The long term side effects of treatment may also lead to psychological difficulties, particularly fears about cancer returning or a new cancer developing. Cancer survivors have reported that they no longer feel safe; a cough, an ache or a bruise take on a new sinister quality (Rowland, 2008).

Survivors have to deal with the side effects and/or late effects of cancer and its therapy for years after completing treatment, such as:

- Fatigue;
- Weight gain;
- Fertility issues;
- Libido problems;
- Fear of cancer recurrence;
- Concerns about developing a new cancer.

According to Macmillan Cancer Support (2008b), survivors have reported suffering from a wider range of lasting effects of cancer, including insomnia, aches and pains, poor appetite and urination and neurological problems, as well as difficulties in managing day to day activities.

DEVELOPING NEW APPROACHES

The DH and Macmillan Cancer Support are co-chairing a project to identify the needs of cancer survivors and their families. The National Cancer Survivorship Initiative (www.ncsi.org.uk), launched in September 2008, aims to ensure that support services are developed to manage the long term sequelae of cancer, both physically and psychologically, and to consider the wider implications for survivors and their families. The initiative aims to improve support for cancer survivors, focusing on the following areas:

- Assessment and care planning;
- Managing active and progressive disease;
- Late effects;
- Children and young people;
- Work and finance;
- Self management;
- Research;
- Information;
- Workforce development and commissioning.

The project highlights that existing follow-up and aftercare support programmes aimed at identifying early recurrence do not support people to move on from being cancer patients. Self management programmes focusing on living well and resuming normal day to day activities would be of greater benefit (Wilson, 2008).

The NCSI published its vision document earlier this year (DH et al, 2010), which commits the initiative to taking steps by 2012 to ensure that cancer survivors in England receive support and that services meet their needs.

It recommended that all survivors should have the following:

- A personalised assessment and care plan;
- Support so they can self manage their condition;

REFERENCES


tinyurl.com/nhs-cancer-plan


FUTURE DEVELOPMENTS

There is still some confusion and debate about whether provision of follow-up care should be the responsibility of health or social care, or whether charitable and patient groups should bear the burden of the economic impact of improvements in survival. Issues such as whether cancer survivors should have an automatic right to free support for physical or psychological damage and treatment, and whether carers have equal access to information and support will cause concern to commissioners of future services.

Nurses will need to consider whether cancer survivors in their care have received relevant follow-up care and access to support which have enabled them to make the best recovery possible and to attain the best quality of life possible.

Part 2 of this unit, to be published in next week’s issue, examines nurses’ role in preventing and managing long term problems associated with cancer survival.