

Survivor services: supporting patients living with and beyond cancer

Helping patients make the best of their lives after treatment starts with thinking ahead before treatment and tailoring support for as long as it is needed. A leader in the field talks about key issues and a new European collaborative group.

Who is a cancer survivor? The US National Cancer Institute suggests that an individual diagnosed with cancer is a cancer survivor 'from the time of its discovery and for the balance of life.' Family members, friends, and caregivers are also impacted by the survivorship experience and are therefore included in the definition.

There are essentially three seasons of survival, as first defined by physician and cancer survivor Fitzhugh Mullan, in 1985 (*NEJM* 313: 270–273):

- Acute survival: begins with diagnosis and is dominated by diagnostic and therapeutic efforts
- Extended survival: the period of remission following initial treatment, dominated by concern about recurrence and residual side-effects of disease and treatment
- Permanent survival: roughly equated with 'cure', where the focus is on long-term risks (such as second primaries) and effects (such as chronic fatigue).



European School of Oncology e-grandround

The European School of Oncology presents weekly e-grandrounds which offer participants the chance to discuss a range of cutting-edge issues with leading European experts. One of these is selected for publication in each issue of *Cancer World*. In this issue Neil Aaronson, from The Netherlands Cancer Institute, Amsterdam, reviews presentations from a recent International Symposium on Cancer Survivorship held last April in Bari, Italy, and organised by the European School of Oncology in conjunction with the Organisation of European Cancer Institutes. Summarised by Susan Mayor.



The recorded version of this and other e-grandrounds is available at www.e-eso.net

I would add a further season:

- Palliative treatment and care/end of life.

The definition of cancer survivorship is important because it defines the target population: does it include only individuals who are 10 years out from their diagnosis of treatment, or also those who are five years – or even one year – out? It also has implications for the focus of care and research: is the emphasis on acute or long-term sequelae, on physical or psychosocial sequelae? It also affects the type of rehabilitation efforts that may be needed.

Growing numbers

Cancer survivors are a growing population, particularly in the developed world, where trends in cancer incidence and mortality in both men and women from 1975 to 2005/10 clearly show increasing incidence and decreasing mortality rates. Cancer incidence is lower in developing countries but mortality is higher. You could argue that cancer is an acute disease with a fatal outcome in developing countries, whereas in developed countries of the world it is becoming more of a chronic disease, increasing the number of survivors. There were around 29 million cancer survivors worldwide in 2008. Twelve million of them were in the US – up from around 3 million in 1971.

About half of people with cancer are diagnosed at the age of 65 or older. This is important because there were 500 million people aged 65 or older worldwide in 2006 and the estimate is this will grow to 1 billion people in 2030. Because so many cancers are diagnosed relatively late in life, many cancer survivors will die of causes other than cancer. Figures show that older survivors of breast cancer are more likely to die of cardiovascular disease than breast cancer (*Breast Cancer Res* 2011, 13:R64) and men who have sur-

vived prostate cancer for at least 15 years are more likely to die of causes other than prostate cancer (*Prostate Cancer P D* 2012, 15:106–110). Survivors of testicular cancer diagnosed and treated before the age of 35 have a 1.7-fold higher risk of dying of circulatory disorders compared to their general population peers (*JNCI* 2007, 99:533–544), while an Australian study showed that cancer survivors are 50% more likely to die of non-cancer causes than the general population (*Cancer Cause Control* 2006, 17:287–297).

Successful cancer treatment does not necessarily mean the end of the effect of the disease. Cancer survivors are at risk for late effects, including: disease recurrence/new cancer; cardiovascular disease; endocrine dysregulation; obesity; diabetes; osteoporosis; upper/lower quadrant mobility and functional limitations; and functional decline leading to disability (*Cancer Epidemiol Biomarkers Prev* 2007, 16:566–571).

At the ESO–OECI International Symposium on Cancer Survivorship, held in Bari, Italy, April 2012, Wendy Makin, from the Christie Cancer Centre, in Manchester, UK, pointed out that chronic survivorship conditions are determined by the type and site of cancer, treatment factors, and patient factors. For CNS [central nervous system] cancers, the late effects are largely endocrine and cognitive in nature. Head and neck cancer patients may have dental, speech and swallowing problems. In patients with breast cancer, long-term problems include cardiotoxicity, pain and lymphoedema, while cancers in the pelvic region are associated with bowel, bladder, sexual and fertility issues. These are all in addition to the ‘general effects of cancer’, which include fatigue, pain, bone loss and changed body image.

Many patients learn to live with,

and adjust to, their limitations over time. Some continue to have chronic problems associated with their cancer, some may encounter new problems such as late toxicity, and they may experience a decrease in quality of life over time, which is compounded by the effects of getting older and by comorbidities that may develop. Yet despite all these challenges, many survivors report enjoying a good quality of life.

Fatigue in survival

Fatigue is ranked as one of the most troublesome symptoms in cancer survival, by both patients and professionals, Ollie Minton, from St George’s Hospital, London, explained at the symposium. In patients on treatment and in advanced disease, prevalence varies from 60% to 90%, depending on the definition. After successful treatment for cancer, many patients suffer chronic fatigue – i.e. fatigue that lasts at least three months. Assessing fatigue can be tricky, because it is ubiquitous and many people in the general population report tiredness. There are more than 20 tools for assessing fatigue in oncology, but the most frequently used are the functional assessment of cancer therapy (FACT-F) – a scale that is used very widely in the US – and the EORTC QLQ-30 fatigue subscale, which is often used in Europe.

Three modalities are used to treat fatigue in cancer:

- Drugs, including haematopoietic growth stimulants and psychostimulants. Studies show a fairly robust effect of psychostimulants, but many patients do not want to take them and physicians do not want to prescribe them.
- Exercise. There has been a lot of interest in exercise as a way of dealing with fatigue complaints. Cumulative exercise programmes have been shown to be efficacious in



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The most recent review of psychological support interventions (*CA Cancer J Clin* 2008, 58:214–230) showed that a variety of cognitive-behavioural, relaxation and other types of psycho-educational treatments are effective in reducing anxiety and depression. The benefit appeared similar for all patients, regardless of their type of cancer, but most of the studies were underpowered for subanalysis, and men and patients from ethnic minorities were under-represented. Few studies have looked at interventions beyond the primary tumour phase, so there is very little evidence base for their efficacy in cancer survivors.

Employment and work-related issues

Anja Mehnert, of the University Medical Centre Hamburg-Eppendorf, in Germany, reported that about two-thirds of people who have had cancer return to work, ranging from 25% to more than 90%. In studies, approximately half of cancer survivors reduced their work schedule, at least temporarily; slightly more than half reported a change in their occupational role; and 25% reported a reduction in their physical or mental work ability or performance levels.

Barriers to returning to work can be work related, including a non-supportive work environment, manual work and physically demanding work, and perceived or actual employer discrimination. Demographic barriers include older age, female gender and lower education levels (*Psycho-Oncol* 2002, 11:124–131; *Acta Oncol* 2007, 46:446–451; *JAMA* 2009, 301:753–762; *Psycho-Oncol* 2010, 19:115–124; *J Cancer Surviv* 2010, 4:415–437; *Crit Rev Oncol Hematol* 2011, 77:109–130). Cancer- and treatment-related barriers include having a poor prognosis or advanced tumour stage. There is

dealing with fatigue complaints, but the magnitude of the effect is relatively small.

- Complex psychosocial and behavioural interventions. Cognitive behavioural, psycho-educational and supportive therapy can be helpful at group or individual levels.

In a Cochrane review of complex interventions in the treatment of cancer-related fatigue, only seven out of 27 studies reviewed showed an overall reduction in fatigue. There is a clear need to better understand the mechanisms of fatigue in cancer survivors so that more targeted and effective treatments can be developed.

Interventions for psychological wellbeing

Depression is very common in cancer. Susanne Dalton, of the Danish Cancer Society Research Centre in Copenhagen, reported on a population-based

investigation of more than 600,000 cancer patients linking cancer registry data to psychiatric hospitalisation records in Denmark for the years 1973–2003. One-year follow-up showed the relative risk of being hospitalised for depression was twice as great among cancer patients as among the general population (*JCO* 2009, 27:1440–45). There continued to be a 40% increase in the risk of hospitalisation for depression from one to four years after diagnosis.

This is just the tip of the iceberg, she suggested, because relatively few patients with cancer develop major depression compared to other psychological problems. A review of 70 studies including more than 10,000 oncology and haematology patients showed depression in 16%, adjustment disorders in 20%, and anxiety disorders in 10%, with 30–40% patients suffering a combination of mood disorders (*Lancet Oncol* 2011, 12:160–174).

a common misconception that patients with metastatic disease no longer want to work, whereas many of them do want to. Other barriers include extensive surgery, endocrine therapy, poor overall health and disability, persistent fatigue and the presence of comorbid conditions and depression.

As part of rehabilitation, patients should undergo assessment and evaluation of work-related skills and demands. Other helpful interventions include: improvement of physical fitness and psychosocial functioning, skills training, occupational counselling and motivational training. A key element is to ensure that co-workers and employers understand what it is to be a cancer survivor, and that these are normal people returning to their normal jobs who have gone through an episode in their lives (*Cochrane Database Syst Rev* 2011, CD007569).

Behavioural changes after cancer

Cancer survivors are at greater risk for second cancers and other comorbid conditions. As a healthy lifestyle is associated with better health and reduced risk for a number of health problems, survivors are often encouraged to make healthy lifestyle changes after completing treatment. Kevin Stein, from the American Cancer Society's Behavioral Research Center, outlined guidelines for healthy living, involving diet and physical activity, that have been issued by several organisations. The recommendations are for a diet high in plant foods, focusing on fruit, vegetables and wholegrain, avoiding red and processed meats, and avoiding high-fat and high-calorie foods.

Cancer survivors are now recommended to avoid inactivity, and to return to normal activities as soon as

possible after diagnosis. This is a major change from seven or eight years ago, when patients were advised to take it easy when tired. As for the general population, survivors should aim to exercise for at least 150 minutes per week – for half an hour on at least five days a week, preferably seven days a week – and also to include strength exercises for at least two days a week.

Weight gain, overweight and obesity are problems for the general population,



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and it is no different for cancer patients. The recommendations are similar: to eat less fatty foods and to exercise. But there is a caution here: women who have undergone chemotherapy for breast cancer often gain weight, and the evidence base suggests that weight-loss and exercise protocols will not necessarily lead to actual weight loss in this group.

A significant proportion of cancer survivors continue to smoke after being diagnosed and treated for cancer, with the highest rates among lung cancer and bladder cancer survivors. There have been only about five randomised clinical trials of smoking cessation programmes directed specifically at cancer patients, and all but one (*Cancer Epidemiol Biomarkers Prev* 1993, 2:261–270) found no significant effect on smoking rates. This

is an area that obviously needs additional attention and research.

All areas of lifestyle change – diet, exercise and smoking cessation – can have an impact on important health outcomes including depression, fatigue, adverse body composition, functional decline and comorbidity. But there are many challenges to successful behaviour change: persistent symptoms and side-effects can get in the way of people being ready to make changes. The time, cost and access to new lifestyle behaviours are things that affect all of us when we try to change, and it is no different for cancer survivors. Survivors will be in different stages of readiness for change; some will have had a very unhealthy lifestyle, and therefore any recommendations will be taken on relatively slowly, whereas others will already be actively involved in changing their lifestyle and can be supported in doing so. Social support issues, lack of knowledge among providers about what to recommend, and setting unrealistic goals can have a negative effect on the outcomes that we wish to achieve.

Emerging models of cancer survivorship care and rehabilitation

In a paper published in March 2012, Catherine Alfano, deputy director of the Office of Cancer Survivorship at the US National Cancer Institute, outlined a comprehensive rehabilitation model that emphasises a joint focus on optimising functional status and quality of life.

This model addresses pre-existing or treatment-related comorbidities, treats chronic effects of treatment, reduces the risk for late effects, and promotes self-management and healthy behaviour. It aims to prevent future problems,

reduce the risk of recurrence, and prevent the spiral into disability, so survivors can preserve their work and social roles (JCO 2012, 30:904–906).

Can we do anything about chronic survivorship conditions? Wendy Makin, from the Christie Cancer Centre, suggested starting at the pre-treatment stage by identifying treatment modalities that are less invasive and less toxic: less invasive surgery, conformal radiotherapy and targeted therapies. Careful patient selection should ensure that patients receive treatments that are going to be effective for them and patients should be prepared by providing them with information about what they can expect. During treatment, and when it ends, survivor programmes should be used to maximise recovery and rehabilitation; patient self-management should be encouraged by drawing up survivor care plans, and patients should be offered after-care and follow-up support services, with capacity for complex case management.

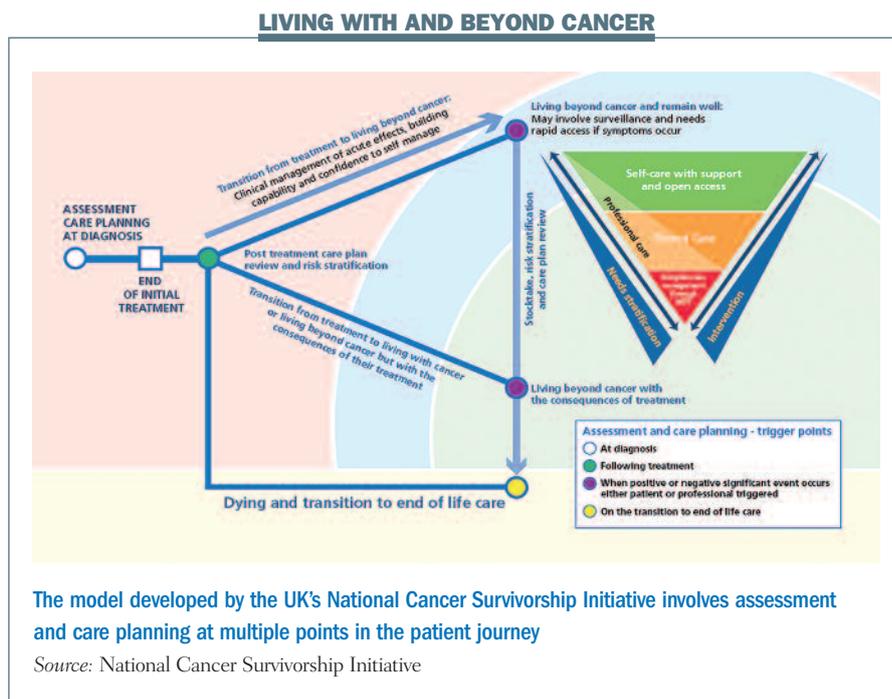
Better screening and identification is needed for patients who have complex problems, with multidisciplinary assessment, including late effects clinics and pathways to support each problem. These should involve a range of specialists and dedicated services in some cases, such as for radiation bowel disease.

The National Cancer Survivorship Initiative

Adam Glaser, clinical director of the UK National Cancer Survivorship Initiative (NCSI), and Jane Maher, chief medical officer of Macmillan Cancer Support, UK, described the approach being taken by the NCSI, a nationwide programme in the UK.

The four emerging principles are:

- risk-stratified pathways of care, rather than one size fits all
- a dynamic personal care plan that arises from an assessment of the



- disease, the treatment, and the individual's personal circumstances
- information provision, which should meet individual needs and should be timely, accessible and promote confidence, choice and control
- encouragement to self-manage with support, and rapid access to appropriate professionals when problems arise.

With regard to risk stratification, the vast majority of patients can self-care, if they have support activity around them that they can call on if needs be. A smaller subgroup of patients has shared care needs, and a much smaller group has complex management problems requiring a multidisciplinary approach.

The NCSI initiative suggests a model of care (see figure) comprising five key elements:

- supporting patients through primary treatment from the point of diagnosis
- promoting their recovery
- sustaining their recovery

- reducing the burden of the consequences of their treatment, and
- supporting patients with active and advanced disease – interfacing with the end-of-life care services.

A European Collaborative Group

Could there be a role for a European collaborative group on cancer survivorship? A discussion at the end of the conference showed strong support. The intent is to involve all the key stakeholders – healthcare professionals, researchers, policy makers and patients – to develop a better understanding of key issues in cancer survivorship research and practice in Europe and to promote high-quality survivorship care and research. A steering committee and international advisory group have been set up.

If you would like to get involved, or if you have any questions about the group, please email Vittorio Mattioli at v.mattioli@oncologico.bari.it, or Neil Aaronson at n.aaronson@nki.nl. ■