



Synopsis

Long-term effects in survivors of childhood cancer

Children with cancer become adults who had cancer¹. Adult survivors of childhood cancer are at risk for medical and psychosocial sequelae that may adversely affect their health status². In the USA, it is estimated that between 1 in 500 and 1 in 1 000 of young adults (20 - 35 years of age) have had a diagnosis of cancer before age 20.

In the 1960s, haematologists recommended as little chemotherapy as possible for childhood leukaemia as 'the children will die anyway so one shouldn't make them ill'.

Chemotherapy was even regarded by some academic haematologists as 'poison' and oncology was not considered a worthy postdoctoral pursuit³. With the advent of more successful therapy, talk of cure became permissible. As the number of survivors grew, patients and their families began to ask significant questions: Will I grow and develop normally? Will I be able to have children? What is the likelihood of recurrence? Will the therapy have any long-lasting effect? There has been a paucity of data to answer these questions, but research is emerging which provides some insight into the health status of survivors of childhood cancer.

The effects of childhood cancer on surviving adults can be divided into health effects and sociodemographic effects. These could result from either the disease or the therapy or both.¹

Hudson *et al.*³ conducted a survey to compare the health status of adult survivors of childhood cancer and siblings and to identify factors associated with adverse outcomes. They studied 9 535 adults who were diagnosed with cancer between 1970 and 1986. Six health status domains were assessed: general health, mental health, functional status, activity limitations, cancer-related pain and cancer-related anxiety/fears.

Forty-four per cent reported at least one adversely affected health status domain. The results further indicated that survivors were significantly more

likely to report adverse general health and mental health, activity limitations, and functional impairment compared with siblings. Sociodemographic factors included being female, lower level of education, and annual income less than \$20 000 (about R130 000 at the time of writing). However, the findings showed that general health as perceived by adult survivors of childhood cancer is 'very good', with only about 10% reporting fair or poor health.

The use of self-reported data and difficulty of interpretation of health status reports by siblings are among the shortcomings of the study.

On the other hand, survivors of childhood cancer often respond to their perceived risk in ways that are beneficial.¹ They would eschew risky behaviours such as smoking, recreational drug use and excessive alcohol use. They often report better quality of life than do controls; this possibly due to denial but it may also reflect an enhanced appreciation of life after therapy.

Concerns about health risk influence self-image and outlook on life, which could affect function at levels which could in turn affect friendship, marriage, education and occupation.¹

Pui and colleagues,⁴ writing in the *New England Journal of Medicine*, found that the risk of a second neoplasm was higher in patients who received radiation therapy, and that the death rate for the irradiated group slightly exceeded that in the patients who did not receive radiation. Irradiated patients also showed a slightly higher unemployment rate. Ross *et al.*,⁵ found that patients who survived brain tumours had an increased risk of being hospitalised for psychiatric disease. The conditions arising in survivors of brain tumour included psychoses of somatic and cerebral causation, psychiatric disorders in somatic disease and schizophrenia and related disorders.

Current research shows that survival rates in many cancers are increasing, and recently Brenner⁶ produced up-to-date epidemiological statistics which indicate that survival rates of children with cancer achieved by the end of the

20th century are substantially higher than previously available statistics have suggested.

Minimal resources are available for long-term programmes for survivors of childhood cancer in the USA. Insurers refuse to pay for screening tests, and programmes that do exist rely on philanthropic support or fiscal support from cancer therapy reimbursements. Research support is rare.¹

A report from the US Institute of Medicine makes recommendations for addressing the situation,^{7,8} among which are:

- Development of evidence-based guidelines on clinical practice to improve follow-up and care of people with a history of childhood cancer
- Defining a minimum set of standards for systematic follow-up care
- Linking primary providers with oncologists and the institutions that treat children with cancer
- Evaluating the methods of delivery of care to the survivors
- Improving access to health care services in general for these people.

Dr F Desai, who has been in the oncology department of the Red Cross War Memorial Children's Hospital says that children with cancer are usually treated in academic centres, and they have a very comprehensive follow-up service. Regular clinics are held for survivors of childhood neoplasms, and even those patients who live far from the hospitals are in regular contact with the staff at Red Cross.

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References

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