Lack of follow-up care puts childhood cancer survivors at risk

Melbourne: A conference of cancer experts will hear today (2/12) that many childhood cancer survivors are missing out on critical follow-up care later in life, with risks including secondary cancers, fertility issues and heart problems.

A presentation at the Clinical Oncology Society of Australia’s (COSA’s) Annual Scientific Meeting, will reveal that around two in five childhood cancer survivors are missing follow-up medical appointments, putting them at risk of adverse health complications that can often be decreased or managed if detected early.

The preliminary research involved a questionnaire of over 270 childhood cancer survivors who had undergone cancer treatment on average 17 years ago. The researchers analysed the key reasons why patients didn’t attend appointments to determine barriers to follow-up care and opportunities to improve health outcomes.

Associate Professor Richard Cohn, from the Kids Cancer Centre at Sydney Children’s Hospital, Randwick, who led the study, said that the biggest barriers stopping survivors getting the care needed include lack of appreciation of the risks (60%), the hidden costs of attending the clinic such as missing work or paying for childcare (40%) and lack of awareness regarding the availability of clinics (30%). Travel for rural and remote survivors was also identified by the researchers as a potential issue.

One in two childhood cancer survivors who didn’t attend follow-up clinics felt they didn’t have enough information on cancer and the late effects of treatment.

Associate Professor Cohn said that while current cancer treatments avoided many of the late effects, that around two in three childhood cancer survivors who had undergone treatment in the past would experience a life threatening or life altering chronic disease later in life.

"With around 80 per cent of childhood cancer patients surviving their cancer and having potentially six or more decades of life ahead, improving the quality of life of survivors is a very important part of paediatric cancer management."

“Complications might not appear for many years after treatment and can range from secondary cancers caused by radiation treatment through to fertility issues, heart problems, susceptibility to skin cancers and psychosocial issues. Many of the problems can be reduced or prevented if detected early."

“For instance, some women who have undergone chest radiation have similar levels of breast cancer risk as those who carry the BRCA gene and should undergo regular screening from young adulthood."

COSA President, Associate Professor Sandro Porceddu, said that the research provided a clearer perspective on the opportunities and challenges in terms of catering for the increasing number of childhood cancer survivors.
“Many childhood cancer survivors are also not aware that the chemotherapy agents they may have received as part of their initial treatment can also increase the risk of developing a second cancer later in life.”

“One of the easiest barriers to break down is awareness and information,” Professor Porceddu said. "While parents often take responsibility for their children’s care, there is a need to make sure the same information and level of care is provided once the child grows up and takes responsibility for their own health."

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*Childhood cancer survivors: What are their motivators and barriers to participating in long term follow-up care?* Will be presented at the Clinical Oncology Society ASM at Melbourne Convention and Exhibition centre at 4pm. Meeting Room 212 & 213 To arrange media accreditation, please email hollie.jenkins@cancer.org.au