

Improving the follow-up of childhood cancer survivors in South Africa

Childhood cancer has become a potentially highly curable disease, reaching survival rates of 80%.^[1] The global childhood cancer survivor (CCS) population is therefore growing, albeit at a fast rate in high-income countries (HICs) and a slower rate in low- and middle-income countries (LMICs). In South Africa (SA), just over 1 000 new childhood cancer cases are diagnosed annually and more than half will become survivors.

However, remission comes at the cost of the risk of development of late effects because of the cancer and/or the cure. Late effects may occur in any organ and up to 40 years after treatment completion. The estimated cumulative prevalence of a serious/disabling or life-threatening chronic condition at 45 years of age was reported as 95.5% and 80.5%, respectively, in a study from the USA.^[2] In addition, CCSs have a shortened life expectancy, mainly due to the development of second malignancies or cardiac and pulmonary late effects.

Lifelong long-term follow-up (LTFU) care is therefore considered essential to ameliorate long-term morbidity. The revised 2016 Erice statement^[3] declared that CCSs have the right to late-effects information and appropriate LTFU care through a multidisciplinary clinic. A formal LTFU programme facilitates monitoring of late effects and early intervention, which should potentially reduce morbidity. Other benefits include increased knowledge about primary cancer diagnoses and potential late effects, improved compliance, and fewer hospitalisations or emergency unit visits. Additionally, better knowledge about LTFU side-effects may facilitate changes made to future treatments to reduce LTFU toxic morbidity.

LTFU models in use include cancer centre- or community-based models or a combination thereof, or distanced methods such as postal, internet or phone-based models. Survivorship care plans (SCPs) detailing treatment received, risk of and surveillance for late effects and individual recommendations for follow-up should be provided in written format and/or online.

Ideally, LTFU is provided by a multidisciplinary team, led by a paediatric oncologist or survivorship expert, consisting of various subspecialists, a dedicated LTFU nurse (who can co-ordinate the service), a social worker and/or a psychologist. In recent years, general practitioners (GPs) and nurses have become involved.

LTFU guidelines direct the surveillance for late effects in an LTFU programme. Groups in HICs have developed several different sets of LTFU guidelines. The International Late Effects of Childhood Cancer Guideline Harmonization Group (IGHG) develops evidence-based or expert-opinion international LTFU guidelines. However, many of these may not be feasible for LMICs owing to limited funding and healthcare provider resources.

In HICs, LTFU is a formal component of care of CCSs. In contrast, LTFU programmes exist in only a few LMICs and there is a lack of reporting on their development, outcomes and impact. A recent scoping review by the authors (unpublished) revealed that LTFU activities in LMICs were in varied stages of development. Seven countries reported using cancer centre-based and shared-care models. India reported using a community-based model and issuing SCPs regularly. Mexico documented a high rate of older CCSs lost to follow-up. Problematic transition to adult clinics (if available) was frequently reported. Five countries used or adapted LTFU guidelines from HICs; two recognised the need for development of more appropriate guidelines.

Currently there is no formal LTFU programme for CCSs in SA, but LTFU service is provided at most paediatric oncology units according to a recent survey.^[4] Fewer than half of paediatric oncologists in SA use an LTFU guideline, and LTFU practices are varied. Most paediatric oncologists (82%) use modified published guidelines. A shared-care model was the most used LTFU model. Almost half of the respondents (48%) shared LTFU care with a colleague in private practice (50%), in a secondary hospital (67%) or in a primary care clinic (25%).

SA needs to develop a national LTFU programme to provide equal and adequate care for the expanding local CCS cohort, especially in the light of the proposed National Health Insurance (NHI) plan. The aim of the proposed LTFU programme is to provide comprehensive medical and psychosocial care to CCSs, to detect late effects, to reduce morbidity and to improve outcome and health-related quality of life. The programme would include CCSs who are in remission or have stable disease ≥ 2 years after diagnosis. We recommend the formal development of an LTFU team consisting of at least a paediatric or adult oncologist, a social worker, a nurse, and other healthcare providers as available. Supportive non-profit organisations, institutional management teams and the national and provincial departments of health should be involved. Continuation of care should take place in the private sector and in public primary and secondary healthcare institutions as appropriate, with support from the original treating paediatric oncology unit.

A shared-care model is the most appropriate model in SA owing to the limited number of paediatric oncologists available and the context of the SA healthcare system. LTFU care should be shared with a colleague closer to the home of the CCS with utilisation of a risk stratification system. This risk-stratified approach to LTFU care has been successfully introduced in many HICs and should assist in focusing resources towards those CCSs who need the most care and significantly reducing visits for those with a low risk of late effects. CCS can be assigned a risk, based on the intensity of chemo- and/or radiotherapy received. Low- and medium-risk CCSs can be followed for 5 years after diagnosis, and thereafter referred to a GP or primary healthcare facility for further LTFU with an SCP from the treating paediatric oncologist. A follow-up every 5 years at the paediatric oncology unit could be considered. High-risk CCSs would require annual LTFU at a paediatric oncology unit or alternate annual visits with a GP or a paediatrician or internist at a secondary healthcare facility according to clear SCP recommendations.

Transitioning of care to adult services is important for successful lifelong LTFU care; both paediatric and adult physicians must therefore be involved. Transitioning of care should be planned and ideally include a shared-care phase between the paediatric and adult physicians.

Future planning involves modification of existing guidelines from HICs with input from all paediatric oncologists to create local SA LTFU guidelines. Every CCS should be provided with a written SCP. A written or electronic copy must be supplied to and discussed with both the patient and the shared-care provider. Ideally, a web-based SCP could be implemented in SA. We emphasise that the SCP is the most important communication tool of LTFU.

In conclusion, comprehensive LTFU care is the essential final phase in the management of a CCS, and should be incorporated into the NHI plan to facilitate uniform, appropriate care for all CCSs to

improve quality-adjusted life-years and potentially reduce morbidity. Shared care with colleagues in different institutions, utilising an LTFU co-ordinator and implementing an SCP, will promote and improve the delivery of LTFU care in SA.

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