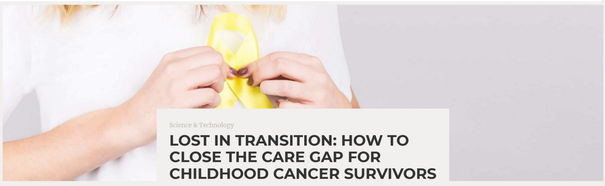

Science & Technology

LOST IN TRANSITION: HOW TO CLOSE THE CARE GAP FOR CHILDHOOD CANCER SURVIVORS

Imelda Coyne | 02.02.2022

As if growing up wasn't hard enough, the transition from paediatric to adult care can be a particularly confusing and overwhelming experience for the survivors of childhood cancer. On World Cancer Day 2022, let's think about how to prevent young people from falling through the gaps!

Over the years, treatments for childhood cancer have become much more successful with many children now surviving into adulthood worldwide. While this is to be welcomed, we also know that nearly 70% of survivors of childhood cancer will go on to develop chronic health problems in adulthood due to the cancer treatments.

Young people affected by late effects will need to make the transition from paediatric to adult health services to receive life-long cancer-related follow-up care. However, this move is a complex process that should take place over a period of time and therefore is not just about switching to another service.

According to best practice, transition should be an "active, planned, coordinated, comprehensive, multidisciplinary process to enable childhood and adolescent cancer survivors to effectively and harmoniously transfer from child-centred to adult-oriented healthcare systems. The transition of care process should be flexible, developmentally appropriate and consider the medical, psychosocial, educational and vocational needs of survivors, their families and care-givers, and promote a healthy lifestyle and self-management."

This is certainly a laudable standard but evidence suggests that transition support and services for young cancer survivors often fail to meet current standards and represent a 'drift away' rather than a clearly planned and coordinated process.

> **"The inadequate transition support and service provision for survivors of childhood cancer has led some to describe the care gap as a *transition chasm*."**

In fact, the inadequate transition support and service provision for survivors of childhood cancer has led some to describe the care gap as a 'transition chasm' – a deep abyss which young people can fall into, meaning they get lost in the healthcare system with potential long-term adverse consequences for their health and welfare.

THROWN IN AT THE DEEP END

There are many reasons for the transition care gap, and some already begin in the paediatric cancer services.

In the paediatric services, children typically receive close care. Yet, when they 'age out' of the services, they are expected to assume total responsibility for their own health care overnight. They must know how to interact with their healthcare provider, share and exchange health data, and know how and where to source help with their symptoms and the long term side-effects of cancer treatment.

They are also faced with the loss of close relationships with their healthcare team and leaving behind a familiar system that they and their families knew how to navigate.

Young people should be prepared adequately for all these changes but it appears that many paediatric centres do not offer a formal programme and consistent information that supports them and their families with the transition to adult-orientated healthcare.

In many cases, discussions about transition may not occur until the last visit to the clinic and young people often experience difficulty obtaining or accessing their medical history. This means that many are left uncertain about their treatment history and potential long-term health problems, such as fertility issues.

MULTIPLE TRANSITIONS

While young people receive regular follow-up care in the paediatric services, it is a different story when they reach adult age, with many not transitioning immediately to a specialist in survivorship care. Their journey differs from patients with other chronic childhood conditions as their cancer has been treated successfully and many are asymptomatic and in good health at this point.

However, childhood cancer survivors still require lifelong follow-up care. Some may stay in the paediatric services until they are 21 years old, while others may have to leave earlier. Therefore, the move usually occurs at a time when young people are undergoing even more transitions on their path to adulthood. These other transitions may involve going to college or university, leaving home for the first time, forming new relationships and/or starting a new job. In some countries that do not provide universal health coverage, young people may also lack health insurance as they age out of parental insurance.

> **"A high proportion of young people experience long gaps in care ranging from two to five years after they leave the paediatric services."**

Consequently, a high proportion of young people experience long gaps in care ranging from two to five years after they leave the paediatric services. They often are forced to seek specialised care when they experience the onset of distressing health symptoms.

LIFE AFTER CANCER

Generally, young people may encounter different types of follow-up care. Some may have to seek care from a variety of specialists in adult medicine depending on their symptoms. However, this can be a daunting prospect. Often it is left to the young person to facilitate and repeat communication between the specialists, and problems are lost or misunderstood in the translation process.

Other young people may be referred back to their family physician but it is quite possible that he or she may lack knowledge of the health risks and the health problems experienced by childhood cancer survivors.

Some young people may have access to a shared care model, which is usually led by a primary care provider such as a family physician in collaboration with a late-effects cancer clinic. Others might frequent a long-term specialised clinic for cancer survivors managed by a multidisciplinary team. This model of care is considered the ideal way to care for these young people but it is not available in many countries.

Current research suggests that risk-based care should be the benchmark for deciding which model of survivorship care is suitable for young people. This means that the young person's treatment history, comorbid conditions and lifestyle behaviours are taken into consideration. This is happening in some countries where specialists' nurses are leading follow-up clinics for young survivors at minimal risk of health problems.

CALL TO ACTION

It appears that young people treated for childhood cancer often face a complex, uncertain and challenging future because of big gaps in transition care and support. Many are confronted with considerable challenges and obstacles to accessing appropriate and timely services to get their needs met.

We know from research that a poorly managed transition is linked to lower clinic attendance, loss of health screening and delayed management of cancer-related health issues, leading to adverse health outcomes for young people.

That is why we need to eliminate the transition gaps in care.

> **"Young people want their voices to be heard and listened to."**

What has been shown to work is a structured programme that prepares young people for successful transition to adult healthcare, as well as close communication and coordination between paediatric and adult services. Transition programmes should incorporate a developmental approach and provide individualised information on late health effects, treatment summaries, self-advocacy and self-management skills, as well as how to navigate the healthcare system.

It is easier to make the case for a well-planned transition to survivorship care than it is to identify what is the best model of care in practice. But we also know that young people want their voices to be heard and listened to. Therefore, we must include their perspectives, preferences, and experiences in the design of transition programmes and services to reduce or ameliorate the care gap.

Let's make life easier for these young survivors!

Imelda Coyne is Co-Editor-in-Chief of the "International Journal of Adolescent Medicine and Health."

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Tags: adolescents, cancer, children, medicine, oncology, transition

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