

Adolescents and young adults with cancer in New Zealand—understudied and underserved

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Every year in New Zealand around 200 adolescents and young adults (AYA) aged 12 to 24 years are told they have cancer. Survival rates for New Zealand AYAs lag behind international comparisons by 7%. This means in the past 10 years, 49 more 15–19 year-old New Zealanders have died of cancer than we would expect. Thirty-four (69%) of these deaths were Māori or Pacific youths, even though they account for less than 30% of cancer diagnoses in this age group.¹

Internationally over the past 20 years, improvement in survival rates for the AYA cancer population have not been as significant as those seen in either paediatric or adult cancer.^{2–4} There are many factors that may contribute to this “AYA survival gap”, including low clinical trial participation, treatment adherence issues and differences in the type of cancers young people present with, disease biology and tolerance of therapy.^{5–8} In addition, due to cancer being relatively rare in this age group, primary healthcare providers and AYAs themselves may not consider cancer as a possibility, potentially leading to diagnostic delays⁹ resulting in poorer treatment outcomes.^{10,11}

“When I went to the doctor they told me it was normal...I went to the doctor at least six times before I was diagnosed.” AYA patient

What distinguishes AYA from paediatric and adult cancer care?

The additional burden of a cancer diagnosis coincides with an already challenging time in which a young person is making the physical, psychological and cognitive transition from childhood to adulthood. Developmentally, young people are becoming increasingly independent and autonomous, are initiating intimate relationships and are beginning to make

important education and career-related decisions.^{12–14} Developmental stage also impacts on the management of their care—there is strong evidence suggesting a significant portion of AYAs experience challenges with adherence.^{8,13} Developmental priorities such as peer influence can also compete with the demands of healthcare.¹⁵ AYA cancer patients therefore have unique needs that neither the paediatric nor the adult approach to management completely addresses.¹⁶

“I was numb. I mean what did cancer mean for my plans for university? I was already planning my courses. What about life and marriage and even kids? I hadn’t thought about kids before but now I had to. And I had to think about how to tell my girlfriend. What would it mean for our relationship?”
AYA patient

Evidence has shown that when we try to fit young people into existing structures and services their needs are often not met. Young people tend to sit on the periphery of cancer care, and they often fall into a “no man’s land” between paediatric and adult cancer services.¹⁷ Furthermore, New Zealand faces additional challenges in our geographical size, small population and cultural diversity. Some smaller DHBs will only see an average of one or two new AYA cancer patients each year, raising the issue of how to ensure young people have equitable access to the highest standard of care.

Where are the gaps?

A Ministry of Health-endorsed review of AYA cancer services in New Zealand undertaken in 2013 highlighted the value of the existing AYA keyworker role but it also identified several gaps in care delivery. These gaps included a lack of clear guidelines and supporting structures for AYA cancer services, which resulted in clinical practice

variation, including time to diagnosis, adoption of treatment protocols, availability of clinical trials, information sharing and participation in multidisciplinary teams.¹ The review also highlighted inconsistencies in the collection, monitoring and reporting of AYA data. Moreover, the survival analysis completed raised a number of significant and alarming concerns regarding disparities and inequalities in outcome for certain ethnic, disease-specific and age-related populations within the AYA cohort as mentioned previously.¹⁸

A way forward for AYA cancer care in New Zealand

While recognising our shortcomings is an important step in creating change, too often the rest of the climb is abandoned. Consequently, strong advocates in New Zealand committed to the idea that the review would only be the first in a long line of actions aimed at addressing unmet needs for AYAs. This commitment combined with the success of the Child Cancer Network and the example set by countries such as the US, Australia and the UK resulted in New Zealand recognising the need for a national framework. The purpose of this framework was to ensure a nationally consistent, well-coordinated and collaborative approach to addressing the needs of the relatively small numbers of AYAs with cancer.

This national framework took the form of The AYA Cancer Network Aotearoa in 2014, charged with providing strategic direction and leadership of AYA cancer care in New Zealand. It is a membership organisation and national resource for health and social providers delivering AYA-specific clinical guidance, support, tools and project management. The Network promotes collaboration across regional and institutional boundaries and helps facilitate the development of innovative initiatives to address unmet needs. An example has been the establishment of working groups that aim to provide sound advice and recommendations on specific areas of care such as early identification of AYA cancers. Simultaneously the Network is developing the national strategy to be released next year. This strategy will address high-priority issues such as improved access to clinical trials, development and monitoring of MDTs, workforce development and more. Overall

it will showcase an optimal model of care tailored to the unique needs of AYAs while ensuring equitable access to high-quality medical and supportive care regardless of where AYAs live.

Setting the standard and beginning the climb

Key pieces of work have been, or are being, undertaken to guide the strategy's development. The first of these has been the creation of the AYA Cancer Standards of Care (SOC). The SOC describe the core elements of cancer care and are a guide and resource for providers to understand and strive to provide optimal care for this age group. The SOC cover a vast array of topics from the diagnostic process to fertility preservation, to psychosocial care, to age-appropriate environments and more. The SOC compliment the previously published 11 national tumour standards to provide a combined comprehensive overview of best care for AYAs.

The SOC are intended for a wide audience, extending across all organisations and institutions that work with AYAs with cancer, including the education sector, the health sector, social services and non-governmental organisation (NGO) providers. The standards are significant as they represent a move away from a model of care that traditionally centred on trying to fit young people into existing structures and services. Instead they aim to explore innovative ways of delivering appropriate and effective care to the meet the distinct needs of the AYA population while recognising the complexities of the New Zealand health system. The Network recognised the importance of informing young people and whānau on the quality of services and care they should expect to receive when diagnosed with cancer. Therefore a series of short videos were developed with AYAs themselves to reflect these standards in a user friendly and age-appropriate manner. It is central to the Network that AYAs are given the platform to self-advocate and shape the Network's messages and goals. In fact every step taken by the Network is supported and guided by consumer input—who better to say what young people want than young people themselves? Both the SOC and the youth videos are readily available on the Network website, which we encourage readers to view and utilise.

The Network recognised the risk that the standards would become just another document shelved among a long line of dusty books. Consequently a specially designed online self-review tool was created and is being used by providers across the country to promote and encourage the implementation of these standards of care. This online tool is a world first for AYA cancer care and it allows users to collaboratively implement the AYA standards of care in driving quality initiatives locally and nationally. It has also been an effective way of raising the AYA profile.

Data collection and monitoring

Planned regular analysis of the New Zealand Cancer registry data is to now occur providing the Network with evidence of emerging trends in AYA cancer and to evaluate how service improvements and changes have impacted survivorship. Patient information and service delivery data collection has also been standardised, allowing the Network to undertake activities such as monitoring clinical trial participation in order to identify and address barriers to improving access for AYAs.

When do you stop being defined as a young adult?

An area of research that has been undertaken following the recognition of a gap in data relates to revisiting the potential causes of the survival disparities identified in 2013. This has included a national retrospective review of specific AYA cancers and also

a study of cancer in the older 25–29 year population. While this age group is currently excluded from the ‘AYA definition’ in New Zealand, internationally they are grouped within this cohort due to the discovery that they experience similar disparities and challenges that younger AYAs confront. Does this translate to New Zealand and if so should we follow suit and extend our age range? The following article explores this important question further.

Conclusion

The establishment of the Network and the subsequent development of services, tools and structures to address the disparities within New Zealand’s AYA cancer population has been an essential and exciting path to weave. However, unfortunately alone, it is not enough. For the Network to flourish and for its goals of equitable, high-quality care for AYAs to be ascertained it relies on the participation and collaboration of the whole sector. For more information and to become a member of the network, please go to <http://ayacancernetwork.org.nz>. The website provides clinical guidance and resources, current and past research, training opportunities, existing AYA clinical and support services locally and nationally.

“It pains me that there are many like myself who unwillingly have to face the brutality of this sickness. But knowing that something... now exists to navigate and enhance the care we as rangatahi receive has me eternally grateful.” AYA patient

Competing interests:

Nil.

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