IMPROVING CARE FOR AYA PATIENTS TREATED WITHIN ADULT HOSPITALS: WHAT CAN BE DONE RIGHT NOW?

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Abstract

As recognition continues to grow in relation to the specific needs of the AYA oncology population, discussion inevitably turns to potential systemic changes that can provide generalised improvements to this population group. While a necessary process, it should not deter discussions relating to how care can be improved 'right now' on an individual practitioner level. There is much that can be learnt from our colleagues working in adolescent medicine that, when applied in an oncology setting, can serve to improve the developmentally appropriate care provided to AYA oncology patients and directly improve outcomes for this vulnerable age group.

All too often the psychosocial and developmental needs of this population are dismissed as superficial to survival outcomes. Yet, the 2006 United States report of the AYA Oncology Progress Review Group identified developmental differences that directly impact upon "care-seeking patterns, adherence to recommended treatment and follow-up care, and ultimately, disease outcomes".[1] Put simply, the thought patterns and behaviours that are directly related to the AYA developmental stage can seriously impact upon treatment and care. Importantly, it is not just the treatment experience that can be impacted by such an approach, but also the quality of survivorship.

The definition of AYA applied in this article is young people aged between 15 and 25, with flexibility to incorporate those older than 25 if their behaviours and lifestyle suggest a closer relationship to their younger counterparts than the adult age group. The challenges faced by AYA patients are more complex and intense than at any other life stage and the vast majority of this population group are currently treated in adult hospitals.[1-2] Understandably, given that the average age of cancer patients treated in the adult health sector is over 60 years, most medical or allied health practitioners do not have extensive experience working with younger patients.

While this may be understandable, as resources need to flow to the areas of greatest need and demand, given its potential impact upon care such lack of available experience is an obvious concern. As recognition continues to grow in relation to the specific needs of AYA cancer patients within the Australian health system, it is incumbent on those who work with these vulnerable young people on a regular basis to identify ways that care can be improved – not just at a systemic level, but at an individual practitioner level.

Young person behind the cancer diagnosis

The Society of Adolescent Medicine recognises the first step in working effectively with AYA patients is to develop an understanding of the developmental changes they are going through.[3] The best care for these patients will come from an appreciation of how diagnosis and treatment may affect the distress levels, self esteem, family dynamics, need for information and communication, peer relationships, self identity, body image, perceptions of future, existential perspectives and other subjective components of the cancer experience.[1]

The developmental changes and challenges experienced by a young person, despite a cancer diagnosis, are enormous. They impact upon every realm of human functioning, including physical, cognitive, psychological and social. The considerable physical changes occurring at this time can generate a high level of self-consciousness and a lowering in self esteem, which can result in the seemingly disproportionate responses to the side-effects of treatment such as hair loss, scaring and weight gain or weight loss. Such side-effects can create extremely strong emotional reactions and while they may seem ridiculous through the lens of adult consciousness, for a young person already grappling with a changing body and relentless self-comparison to peers and celebrities, it is a very real concern. The cognitive changes occurring during this time are also meaningful, as this is where the most complex stage of cognitive development, formal operational thought, is achieved.[4] However, even those young people who are capable of complex thinking and understanding complex issues, are more likely than their adult counterparts to be oriented to the present, and may regress in their capacity for complex thought under the extreme stress of a cancer diagnosis and its treatment.[5] These developmental challenges can have direct consequences for communicating with AYA patients, the adherence of the young patient to treatment regimens and their responses throughout treatment to changes in prognosis or treatment plans.

The psychological development of the adolescent and young adult primarily involves developing a self-concept and a strong sense of self. This can be significantly compromised if a large proportion of the AYA's life is taken up with treatment and recovery.[6] To avoid the 'sick role' becoming central to the AYA's sense of self, it is essential that the young patient is exposed to opportunities to be as 'normal' as possible. This includes continuing with schooling, developing intimate relationships, separating from parents, becoming more independent and interacting with peers.

The treatment team has a powerful role in determining whether exposure to such normal developmental experiences can occur and it is incumbent upon them to consider these issues when working with AYA patients. The evolving independence of the young person is a further developmental pressure that can create specific challenges. There may be strong ambivalence associated with the involvement of parents in their care. This can serve to influence the level of communication and negotiation required when parents and other family members are involved.

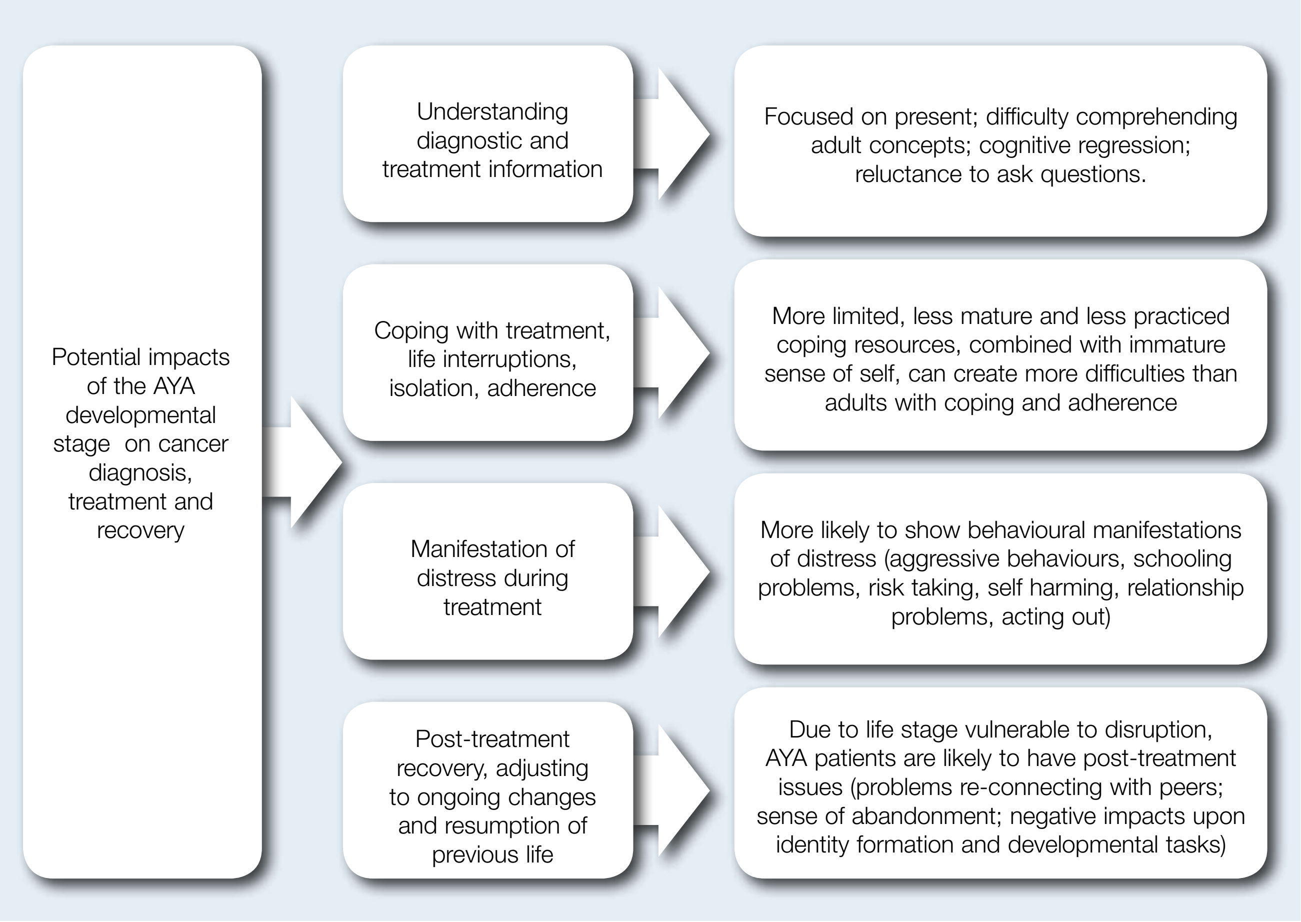
In combination, these changes create unique physical, psychological and behavioural patterns that can directly affect the cancer experience (see figure 1). Although a cancer diagnosis and its treatment will inevitably have a lasting impact upon the young person, the provision of developmentally appropriate care to AYA patients can significantly impact on how they adapt to their experience.[7] Combined with the best medical care available, age appropriate supportive care can minimise the distress experienced during treatment and maximise post-treatment recovery and survivorship.

What can be done to improve care now?

Working with AYA cancer patients in the adult sector may be the only time adult-trained and focused clinicians are forced to work with a younger age group. There are a number of simple strategies that can be used that can have a significant impact upon quality of care. These strategies do not require additional funds, a re-organisation of treating teams, or a revision of treatment protocols. They are all simple, but effective ways to improve the developmentally appropriate provision of care.

Provision of a confidential relationship between patient and practitioner is an integral part of best-practice care. However, a confidential relationship with the AYA patient can be compromised when parents are significantly involved in the care of the young person. AYA patients may be reluctant to disclose information relevant to their care when others are present or may later be informed.[8] A range of issues occurring in the life of the young person may directly impact upon their care; issues such as drug and alcohol use and abuse, sexual experimentation and emerging mental health problems. All of these issues need to be openly and honestly discussed with the AYA patient in a confidential environment. This requires ensuring ample opportunity for the young person to meet with members of their treatment team without parents being present. Indeed, due to the often ambivalent relationship

Figure 1: *Impacts of AYA development on responses to diagnosis and treatment*



between patient and parent, this should be insisted upon by the clinician.

Young people are at a stage of life where development dictates that they push the boundaries of recognised establishments and authorities. Given this, it is essential that discussions with AYA patients take on a tone of consultation and collaboration, rather than dictating care. An overly controlling approach can have a direct consequence on treatment outcomes and has been shown to impact upon treatment adherence with this age group.[9] Discussions should always be directed to the patient and a paternalistic approach should be avoided, as should the urge to form a united front with the parent against the young person.

AYA patients are unlikely to have the same communication style as their treating professional and it is important that the professionals working with them are mindful of such differences.[10] This involves tailoring the delivery of the information to the age of the patient and recognising that, when under extreme stress, the AYA patient may have increasing difficulty understanding challenging or confronting information. Information should be provided in a number of different ways to improve understanding (verbal, written and audiovisual). It is also important to keep in mind how intimidating the medical environment may be for a young person and this may be characterised by a reluctance to ask questions. This should not be interpreted as a lack of desire to understand what is going on.

Young people are extremely internet savvy. It should be assumed by those working with this age group that this computer literate generation will inevitably turn to the internet to find further information. Providing appropriate websites to access safe, authoritative and age appropriate information is a key part of providing diagnostic information to this age group.

Unlike the paediatric system, the adult health sector generally requires cancer patients to navigate the system solo. This can be a daunting task for any adult, but can present an overwhelming situation for the AYA patient. The designation of a key worker does not require a complex reorganisation of tasks or roles. It can be as simple as a member of the multi-disciplinary treating team acting as a contact and liaison person to offer consistency, advocacy and support. The role of this person as a primary contact should be made explicit to the patient.

The inherent complexities associated with the AYA stage of life necessitate a preventative approach in the psychological and emotional care of these young patients. Recognising that this is an area of oncology care that is generally overstretched, it is appropriate that care is prioritised to those most at risk. The AYA patient automatically falls in to this category. Lack of supportive care has been indicated as a factor associated with adherence issues with this age group.[1] At a minimum, all AYA patients should have access to the support provided by a social worker at the earliest time possible.

In what can seem to be a contradiction to earlier points, working with AYA patients often requires a familial approach. Although it can be a difficult balance to achieve, it is an area of practice that is important to embrace when working with this age group, as the practical needs of the patient are enmeshed with the needs of the family. Issues for consideration include: parental problems at work; increased costs due to travel; issues associated with living away from home; increased family stress; caring for siblings; anxiety and depression of family members; and the needs of intimate partners.[11] The needs of younger siblings are a specific area of concern that should be addressed in a timely manner to reduce the strain on the patient and their family.[12]

Survivorship is an area of AYA oncology care that has very little resources allocated to the provision of services.[6] However, it is of great importance to the ongoing development and functioning of the young person. Disruptions to education, interruptions to the exploration of intimate relationships and issues with ongoing dependence on parents all contribute to post-treatment difficulties. Oftentimes, due to the complexities of the treatment period, it is not until treatment finishes that the emotional processing of the past months or years occurs. Yet, survivorship supportive care and counselling has been identified by AYA patients as one of the primary unmet needs of this age group.[13] The referral of young survivors to appropriate supportive care post-treatment is a simple and effective way to improve care provision in this area. Additionally, the provision of a full treatment summary detailing treatment received, complications experienced and potential long-term implications is important for this very transient population group.

Conclusion

Working towards improving care for AYA patients requires a collaborative approach across the range of multi-disciplinary professionals involved in their care. While it is undeniable that medical research, treatment protocols, referral pathways, clinical trial access and improved relationships between the paediatric and adult sectors will improve the current disappointing survival rates for this age group, the recognition and understanding of the young person behind the disease and their age-based needs, is also a necessary step. The development of the best treatment plans in the world will not be enough for these young people if an environment that supports their coping and promotes their ongoing development cannot be achieved. Fortunately, this is an area of AYA oncology care that can be improved right now.

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