

## Distress Screening in AYAs with Cancer

Routine distress screening can assist with early identification of young patients at risk of negative psychosocial outcomes, monitor their progress in coping with their illness and identify their support needs. While screening alone cannot address patient support needs, when paired with effective care planning and referral to support services, this allows clinicians and patients to take a preventative approach to psychosocial health.

We know that the psychosocial support needs of Adolescent and Young Adult (AYA) cancer patients can be very different from paediatric and adult patients. Their ongoing cognitive, emotional and social skills development and their desire for independence can create challenges for clinicians in identifying support needs and managing their care. Using age-appropriate screening, care-planning and psychosocial assessment tools can improve clinicians' ability to readily identify which patients are in need of additional psychosocial care and ensure that they receive appropriate support as their needs evolve.

### **The distress thermometer and problem checklist screening tool, care plan and psychosocial assessment measure**

Until recently, no psychosocial screening tools had been developed to specifically meet AYA needs. The AYA-specific Distress Thermometer and Problem Check List screening tool, Care Plan proforma and Psychosocial Assessment Measure as outlined in the *Adolescent and Young Adult Oncology Psychosocial Care Manual* (CanTeen, 2011) are the first available tools for assessing and planning care specifically for AYA oncology patients.

### **Developing the screening tool, care plan and psychosocial assessment measure and associated manual**

CanTeen Australia developed these tools, partnering with ONTrac at Peter Mac Victoria Youth Cancer Service, and with input from Australian AYA clinicians and AYA patients. A scoping study was conducted to identify relevant psychosocial assessment tools. Published articles almost exclusively related to the adult or paediatric patient

groups. No articles presenting AYA oncology care plans or screening tools were found, although relevant adult and non-oncology specific adolescent instruments were identified. Stakeholder feedback was then sought through interviews and discussion groups to identify the most appropriate tools, and develop and refine the tools to address the specific requirements of AYA patients and clinicians.

### **Feedback from Clinicians, Patients and Survivors**

Clinicians identified the well-validated (in the adult population) National Comprehensive Cancer Network's *Distress Thermometer and Problem Checklist* as the best quick measure to screen for distress, pending age-appropriate modifications. Describing the development of these instruments, Palmer, Patterson, & Thompson (2013) noted that *"given the absence of any measures that have been specifically developed for or validated with the AYA population, all clinicians were mindful that the "perfect" measure did not yet exist, and as such, any available measure would come with compromises. It was agreed by all present that a well developed yet not validated AYA-specific measure would be of greater clinical usefulness than using a validated measure that was not appropriate for the age group or setting"* (p.3). The Care Plan was developed to partner with the screening tool as a quick, easy to complete and updatable planning pro forma to facilitate communication, partnership building and self management. Goldenring and Cohen's (1988) *HEADSS Assessment* was identified as the ideal psychosocial assessment tool, provided it was revised for use with AYA oncology patients. The tools were iteratively developed with input from stakeholders and a manual covering best practice in screening, assessment and care planning was developed. Palmer et al. (2013) noted that *"all clinicians reported an in-principal desire to utilize a nationally standardized screening tool and assessment measure. They were very responsive to the idea of a national approach, and were keen to enhance cross-institutional data collection and collaboration"* (p.3). For further information on the development of these AYA-specific psychosocial assessment and care tools, read the [Palmer, Patterson, & Thompson \(2013\) article](#).

Additionally, the South Australian Youth Cancer Service developed an Adolescent and Young Adult Oncology Psychosocial Survivorship Care Process for AYAs who have completed treatment. It too contains a modified version of the screening tool and PCL, and care plan pro forma.

## Best practice in AYA distress screening and delivery of care

These tools currently represent an Australian best-practice standard for assessing and responding to AYA distress and are better targeted than existing paediatric and adult tools. By incorporating these tools into the national YCS model supported by the Department of Health, we are seeking to improve the consistency of identification of AYAs in need of psychosocial support. Completion of the screening tool has been identified as an important reportable marker of the success of the YCS model as it is a crucial step in identifying young patients at risk of negative psychosocial outcomes, and planning and delivering best practice, preventative care. Consistent use of these tools also supports the collection of Australia-wide data enhancing our understanding of the psychosocial well-being and mental health outcomes of young people living with cancer.

## Evaluation of the screening tool

Implementing new standards of assessment and care in practice, whilst challenging at times, is essential; and ensuring that new tools are thoroughly validated is vital. A national project is currently underway to validate the AYA modified Distress Screening tools and examine their clinical utility. The abstract for the upcoming article on this project by Patterson, McDonald, Anazodo, Costa, Wakefield, White, Thompson, & Osborn (2015) in the journal *Clinical Oncology in Adolescents and Young Adults* can be found [here](#). We will be recruiting AYA patients, AYA survivors and YCS healthcare professionals and we have recently begun data collection with patients in NSW and the ACT. Data collection is imminent in SA and state and hospital ethics in QLD, VIC, NT and WA is progressing. Thanks to all who have assisted with the ethics process and recruitment to date. Your commitment to this important project is greatly appreciated! If you would like any further information about this project please contact A/Prof. Pandora Patterson: [Pandora.Patterson@canteen.org.au](mailto: Pandora.Patterson@canteen.org.au).

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