

A national approach to improving adolescent and young adult (AYA) oncology psychosocial care: The development of AYA-specific psychosocial assessment and care tools

SUSAN PALMER, PH.D.,¹ PANDORA PATTERSON, PH.D.,² AND KATE THOMPSON, M.A.S.W.³

¹AYA Psychologist, Melbourne, Victoria, Australia

²CanTeen Australia, Sydney, New South Wales, Australia

³ONTrac at Peter Mac, Victorian Adolescent & Young Adult Cancer Service, Peter MacCallum Cancer, Melbourne, Victoria, Australia

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ABSTRACT

Objective: Age-based screening tools and assessment measures are crucial to the provision of best practice care for adolescent and young adult (AYA) cancer patients. Unfortunately, there are limited psychosocial tools developed for this age group and pediatric or adult measures are often distributed with the assumption that they are “close enough.” We describe a collaborative Australian project that strives to improve what currently exists for the psychosocial assessment of and planning for the 15–25-year-old age group.

Method: Using the National Comprehensive Cancer Network’s Distress Thermometer and the HEADSS Assessment as a foundation, the tools were developed in consultation with Australia’s leading AYA clinicians, AYAs currently undergoing medical treatment, and a group of AYA survivors through a process of discussion groups and clinical interviews.

Results: The result is the first available AYA-specific screening tool, care plan pro forma, and psychosocial assessment measure developed for use within the oncology sector. These new tools will assist clinicians working with this population group to support psychosocial coping during active treatment and promote healthy post-treatment survivorship.

Significance of results: Over time, further validation procedures will add to the veracity of the measures. Until then, these measures represent the best available in Australia. They highlight a clinically recognized minimum standard of care that all young cancer patients, regardless of treatment location, have the right to receive.

KEYWORDS: AYA, Psychosocial screening, Assessment

INTRODUCTION

The psychosocial support needs of adolescent and young adult (AYA) cancer patients 15–25 years of age are different from those of patients of other ages. AYAs’ developmental stage has them straddling adolescence and emerging adulthood. Their cognitive, emotional, and social skills are under development

while their desire for independence and separation from parents is increasing. This combination can create a challenging environment for the clinician.

A preventative approach, comprising regular psychosocial screening and care planning, enables treating teams to identify those patients at risk of a negative psychosocial outcome, monitor the progressive coping of the patient, and identify areas of need requiring additional care and support. This approach ensures that young people receive the support they need, even as their needs change. To support such an approach, age-based psychosocial tools are

Address correspondence and reprint requests to: Pandora Patterson, CanTeen Australia L11, 130 Elizabeth Street, Sydney, New South Wales, Australia. E-mail: pandora.patterson@can-teen.org.au

essential. To date, there exist a number of robust psychosocial measures developed for both adult and pediatric patient groups. However, as yet, no such measures have been developed specifically to address their developmental differences and specific requirements of the AYA population group of oncology patients. This has the potential to directly impact the psychosocial support and assistance provided to this age group. Over the past decade, there has been a notable increase in interest in this area of oncology in Australia, with various attempts made to redress this potential inequity in psychosocial care provision.

The Australian Sociopolitical Context

In 2005, the Australian Senate Community Affairs References Committee conducted an inquiry into cancer treatment and services in Australia. Whereas many recommendations from this inquiry aimed to improve the current state of cancer treatment and services overall, a few were specific to the AYA population. These included the recommendations that (1) the federal government consider the development of appropriate referral pathways that take account of the particular difficulties confronted by adolescents with cancer and (2) the state governments recognize the difficulties experienced by adolescent cancer patients being placed with inappropriate age groups and examine the feasibility of establishing specialized adolescent cancer care units in public hospitals (Community Affairs References Committee, 2005).

In response to these recommendations, Cancer Australia, the National Government Agency charged with improving cancer outcomes on a national level, developed a collaboration with the nonprofit organization CanTeen, the Australian Organisation for Young People Living with Cancer, to develop a national service delivery framework (NSDF) for AYAs with cancer (CanTeen and Cancer Australia, 2009). This age-specific service delivery framework delineated five key needs for AYA cancer patients, one of which was the development of age-specific psychosocial assessment at diagnosis and throughout treatment. Subsequently, in 2010, the Australian government provided CanTeen with finances to establish and manage the Youth Cancer Networks Program (YCNP). The development of the AYA Oncology Psychosocial Assessment and Care Process is one of the national projects funded by this program.

METHOD

Scoping Study

The first stage in developing the AYA Oncology Psychosocial Assessment and Care Process and tools

involved conducting a scoping study to identify relevant psychosocial assessment tools and methodologies; access information relevant to the development of psychosocial care plan guidelines; and determine current best practice approaches in psychosocial screening and assessment of AYAs living with cancer. The scoping exercise was three pronged, involving correspondence with identified leaders in the field, a literature review, and an internet search of e-health websites.

MEDLINE[®] and PsychLit searches were conducted to identify published articles detailing AYA psychosocial screening and needs assessment measures, validation of adult or child health needs measures with AYA populations, and healthcare plans that could be revised to be AYA-specific. The literature search produced a relatively small number of relevant articles. Although psychosocial screening and needs assessment is a growth area in oncology, published articles almost exclusively related to the adult or pediatric patient groups. The most relevant research in this area continues to be that published by Zebrack and colleagues in the United States. However, this work uses a broader age range to define AYAs (up to 40 years old) and is predominantly focused on survivorship needs. No articles presenting AYA oncology care plans or screening tools were found, and the most relevant AYA assessment, although not oncology specific, continues to be the HEADSS assessment (Goldenring & Cohen, 1988) which is a screening test for adolescent patients.

From this process, a list of available measures was developed. Screening tools, assessment measures, or care plans that did not have appropriate language, lacked identified needs, or were overly complex were removed from further consideration. The remaining measures formed the basis of discussion for two discussion groups: one with AYA clinicians and one with AYA survivors.

Consultation with AYA Clinicians

A select group of 10 AYA clinicians from around Australia participated in a 90 minute discussion to debate the results of the scoping study and the type of assessment tool and care plan they would find most beneficial in their current roles. Each clinician was a representative of the specialist AYA oncology centers in Victoria, New South Wales, Queensland, South Australia, and Western Australia. Experts in the clinical areas of nursing, social work, psychology, and pediatric oncology, as well as a survivorship/late effects nurse specialist, were also present.

The battery of measures sourced through the scoping study was presented to the participants for rating. The measures were separated into screening

tools, assessment measures, and care plans. The group divided itself into pairs to assess and then rate each of the measures on a scale of 1 to 10. Each pair comprised a mix of clinical backgrounds and treating center locations. The rating criteria were: relevance to AYA populations, clinical usefulness, timeliness, having available resources for follow-up and referral, and level of clinical expertise required to conduct the assessments. Once completed, these ratings were shared with the group and discussed. A final group consensus was reached for the rating of each measure.

Consensus was achieved without considerable disagreement. 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. Therefore, a number of suggestions were made as to how to improve available measures to make them more useful to clinicians. Suggestions included the possibility of combining sections of current measures to ensure that all relevant topics were addressed, and to revise available measures validated on different population groups to become more AYA-relevant.

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. All agreed that a multiple-pathway approach to psychosocial management was most appropriate, and that whereas the outcome should be aspirational in terms of achieving best-practice outcomes, it should also be realistic given the varying degrees of clinical resources and support around the country.

Consultation with AYA Cancer Survivors

A group of 11 AYA cancer survivors attended a 2 hour discussion at the Victorian CanTeen office. Six female and five males attended. Ages ranged from 16 to 24 years, with an average age of 20 years. Participants had a range of cancer diagnoses, including lung carcinoma, thyroid cancer, Hodgkin’s lymphoma, Ewing’s sarcoma, acute lymphoblastic leukemia, and testicular cancer. Although there was one patient who was approaching the last week of her active treatment, the remaining participants were survivors who had completed their cancer treatment.

They were, on average, 20 months post-diagnosis with a range of 10 months to 36 months. The young people had been treated in a variety of institutions across Victoria, including small private hospitals, large adult teaching hospitals, a pediatric hospital, and regional settings. A number of patients had experienced care across more than one treating institution.

All participants expressed their desire to improve AYA care and had attended the discussion group with the intention of sharing their experiences and “expertise” in the hope of doing so. As the project goals were explained, all indicated that they supported the idea of regular psychosocial screening, and appreciated the potential benefits of psychosocial support during treatment. However, when provided with the collated example screening tools for discussion, concerns were raised regarding the “tone” of the measures. Many felt that the existing measures were negatively focused and were not addressing the topics that were of most importance to them. The language of a “screening tool” was not liked by some as they thought it sounded too clinical and seemed to indicate to the young person that “something was wrong” with them. An alternative was not suggested, but it was agreed that this would be an area to discuss further. Issues such as concerns about fertility, hair loss, ability to participate in sports, maintenance of fitness, body image, and impact on normal social activities such as “drinking with friends” were all highlighted as important areas needing inclusion in an age-appropriate screening tool. Because of time constraints, limited time was spent discussing the care plan that would accompany the screening tool, but it was suggested that an informal and collaborative approach might be better for young people, as they reported feeling intimidated by clinical processes that were overly formalized.

All participants agreed that the use of a standardized AYA psychosocial screening tool and care plan would have improved the psychosocial care that they had received throughout their cancer journey. Most saw the benefit of such tools as being the role they play in highlighting issues to think about during treatment and in opening discussions about getting help. To further improve information provision during the initial stages of diagnosis, it was suggested that a “tick box” section be added to any AYA screening tool that highlighted the most important topics to discuss with any new AYA patients. Key topics participants suggested listing were: psychosocial and peer support options, entertainment options, ideas for improving comfort, information about fertility implications, information about alcohol and drug use while in treatment, ideas to improve communication with treating teams in an intimidating

environment, and the name and role of the AYA key worker. The provision of such information was seen to be a minimum requirement at this stage of the journey. Many felt that they had found this information out too late in their own experience or not at all. In relation to the accompanying psychosocial care plan that would be developed following the administration of the screening tool to formalize the clinical response to the needs identified in the screen, the primary benefit identified by the survivor group was the assumed improvement in communication among the treating teams, ward staff, and general practitioners, and when transferring care to other hospitals.

AYA Patient Interviews

In order to enhance the consultations of the discussion groups, three patient interviews were conducted at Peter MacCallum Cancer Centre. All patients were female, with an average age of 21 years, and all were receiving their first or second round of chemotherapy treatment for Ewing sarcoma. The benefits of discussing the project with current patients, as opposed to survivors, were assumed to be the clarity of specific needs identified at the diagnosis and early treatment stages. As these patients were still experiencing an immediate period of need for support and information they did not yet have the retrospective perspective garnered from the survivors.

The feedback provided by the current patients indicated that practical information and support to navigate workplace issues, such as leave entitlements, and accessing support from CentreLink (a statutory authority responsible for delivering human services on behalf of agencies of the Commonwealth Government of Australia), were the greatest concern during the early stages of the cancer journey. Although information regarding emotional and social support options were welcome, they were unlikely to be accessed at this stage. Information regarding internet-based support options were reported to be of greater use to the patients as they learned to find their way in the health system and make sense of their diagnosis within their existing support networks.

Ongoing Clinician Input

Following the discussion groups and interviews, all of the clinicians involved in the discussion groups remained involved in the development of the tools through regular e-mail and phone contact. The clinicians assisted with the incorporation of feedback from the discussion groups and interviews, and provided ongoing iterative feedback throughout the development process.

RESULTS

AYA Oncology Psychosocial Screening Tool

The screening tool was developed using the results from the scoping study and feedback from the clinician discussion group. It was then revised from the first draft using feedback from the survivor discussion group. The tool has four main areas that were developed to meet the needs of this age group and promote a collaborative patient–clinician relationship: the distress thermometer, the check list of “areas of concern,” the tick box for information provision, and the signatures.

The results from the clinical discussion group were very clear; all clinicians felt the distress thermometer (National Comprehensive Cancer Network, 2011) was the best quick measure for distress; however, all agreed that a “check list” of areas of concern that related to the distress levels identified by the thermometer was necessary to provide a full picture of patient need. Therefore, using existing “check lists” and combining AYA-specific topics that were highlighted by the clinicians (and then the survivors), an accompanying list highlighting areas of AYA need was developed. Included in the measure was a “tick box” section that highlighted the areas of information provision that all young people should receive at each administration of the screening tool. This provided a “double check” for clinicians to ensure that they have covered important areas and also provided a prompt for the young person to ask questions about the topics identified. The final section of the screening tool was the signature section at the bottom. This was included to promote the “teamwork” approach to patient management. By including the dual signatures, the patients were identified as having completed the measure, understood the process, and been informed of the next steps, with clinicians acknowledging their role in the management of the patient and the requirement to schedule an appointment to develop the care plan.

AYA Oncology Psychosocial Care Plan

The scoping exercise did not highlight any available care plan that satisfactorily met the needs of the clinicians and AYA patients. Despite there being a small number to present and discuss at the clinical discussion group, none were identified as appropriate. Therefore, the aim of the care plan was to bring together the wants and needs of the clinicians as discussed in the discussion group meeting. This included creating a document that (1) was related to the screening tool, (2) was quick and easy to complete, (3) was AYA specific, (4) could be used as a communication tool among professionals, (5) could be updated

when necessary, (6) was completed in partnership with the patient, (7) provided details for self-management by the patient where appropriate, and 8) incorporated a “flag” system for highlighting areas of major concern.

Depending on time available and depth of need, the care plan was developed so that the clinician could either fill in the form using a simple coding system, or provide full detail in the space provided. Importantly, it was determined that details of any referrals made must be included on the care plan. This meant that the young people were fully aware of names and contact details for any follow-up and could manage their own care if desired. However, the patients were keen to stress that this “self-management” approach should be an option for the patient to choose and not an assumed part of AYA psychosocial care. Many indicated that there were stages during their own treatment when they were too unwell physically or emotionally to manage their own care. They stressed that they wanted the “self-management” option presented to them with the recognition that they could take the lead if they were well enough to do so.

The care plan also incorporated a space to record the details of the lead clinician identified to manage the patient’s care. This served a number of purposes; first, it provided the details of the clinician that the patient could contact to address any concerns or answer any questions. Second, it provided details of a contact person to other individuals involved in the patient’s care who might receive copies of the care plan (e.g., ward staff, general practitioners [GPs], shared care clinicians, palliative care professionals). Finally, it promoted the discussion of patient management and the appointing of key workers among the treating team.

Once again, there was a signature section at the bottom of the care plan that was required to be completed by both the lead clinician and the patient. At this stage, the date for the next appointment to administer the screening tool would also be recorded at the top of the page. The purpose of this was to promote adherence to the care pathway and provide a sense of consistency for the patient.

AYA Oncology Psychosocial Assessment Measure

The readily available HEADSS assessment is a widely used adolescent psychosocial assessment measure. All clinicians agreed that this measure remained the most appropriate tool to use when conducting assessments on the AYA cancer population. However, all agreed that revisions or additions to enhance its suitability for oncology patients and the

AYA group were necessary. The discussion group suggested that each of the areas of inquiry have clear prompts for discussion and information gathering. This information would then form the foundation for the development of the working care plan. A section to highlight the strengths young people have to draw on during their cancer journey and to identify the areas of possible risk was also deemed to be important. As highlighted by the survivor discussion group, it was also deemed important to address the areas of young people’s lives other than their diagnosis, and identify any important upcoming events that could enhance normalization, promote adherence to treatment, and support healthy survivorship. As was also stressed by the survivor group, management of the patient must involve consideration for implications of survivorship. This includes issues relating to education, relationships, autonomy, and future planning.

AYA Oncology Psychosocial Care Manual

A manual detailing administration requirements, training expectations, and guidance for clinicians was developed to accompany these new tools. The manual covers topic areas such as information provision for AYA patients, referral requirements, and clinical guidance for each of the new tools. The manual was developed to provide guidance for the clinician administering the tools, and it explicitly states that it is not to be used to the exclusion of relevant institutional guidelines and protocols.

DISCUSSION

The AYA oncology psychosocial assessment and care tools and the accompanying manual represent current best practice in the psychosocial screening, assessment, and care plan development for AYAs with cancer in Australia. Developed in conjunction with Australia’s leading clinicians over an 8 month period, these documents represent an important milestone in the provision of age-appropriate supportive care in Australia. Supported by the establishment of AYA-specific cancer services across Australia, these care tools aim to improve the current psychosocial health outcomes of young people living with cancer.

Committed to a national approach to the delivery of psychosocial care, all of the AYA-specific cancer services in Australia have adopted the AYA oncology psychosocial assessment and care tools presented in this article. The use of these tools on a national scale will support clinicians in improving psychosocial care for this population group, regardless of treatment location. This national approach will improve the standardized delivery of a best-practice model of care and

will support the collection of national data. National data collection and analysis of the data will further enhance our understanding of the psychosocial well-being and mental health outcomes of young people living with cancer.

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REFERENCES

- CanTeen and Cancer Australia (2009). *National Service Delivery Framework for Adolescents and Young Adults with Cancer*. Canberra, Australia: Australian Government, Cancer Australia.
- Community Affairs References Committee (2005). *The Cancer Journey: Informing Choice. Report on the Inquiry Into Services and Treatment Options for Persons with Cancer*. Canberra, Australia: The Senate Community Affairs References Committee.
- Goldenring, J.M. & Cohen, E. (1988). Getting into adolescent heads. *Contemporary Pediatrics*, 5, 75–90.
- National Comprehensive Cancer Network (NCCN) (2011). *Clinical Practice Guidelines in Oncology for Distress Management: Version 1.2011*. Fort Washington, PA: National Comprehensive Cancer Network.