The use of the modified Distress Thermometer in identifying and managing distress amongst AYA cancer patients

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AYA Psychosocial Support Needs*

Specific needs

- Psychosocial support needs differ from other patients
- Biological, cognitive, emotional and social skills still developing
- No longer a child, not yet an adult – distinct developmental period

Physical and sexual maturity
Brain and emotional development
Importance of relationships with peers and romantic partners
Establishing a different relationship with parents
Establishing independence
Identity exploration and formation
Exploring study / work options
Future plans and anticipating one’s life trajectory
Mental health problems account for around 50% of the burden of disease for young people; incidence of mental illness in young people is the highest of any age group.
Standardised Screening, Assessment, & Care Planning for AYAs

- Absence of psychosocial tools available for the AYA cancer population (1)
- Age based measures are crucial to best practice care
- Preventative approach
  - identify patients at risk
  - monitor progressive coping
  - identify areas of need and addresses changing needs
- Allow objective measurement of distress and comparisons over time
- Promote robust research
- Support coping during treatment and promote healthy survivorship
- Clinically-recognised minimum standard of care

AYA Oncology Psychosocial Care Manual

The review process
- Review of available scales, assessments and care plans
- National and International experts invited to share tools in use

The development process
- AYA patient working group
- Working group of Australia’s leading AYA clinicians

Ongoing consultation and revision
- Clinical working group

First available AYA oncology specific tools and assessments
AYA Oncology Psychosocial Care Pathway*

**Screening Tool**
- Identify current distress
- Identify current needs
- Provide information
- Build rapport
- Highlight ongoing involvement
- Act on immediate need

**Care Plan**
- Develop plan
- Act on current need
- Establish rapport
- Identify referrals
- Create document for circulation
- Empower AYA patient

**Assessment Measure**
- Revise and refine Care Plan
- Develop in-depth understanding of patient
- Understand risk factors and protective factors
- Promote healthy survivorship
AYA Oncology Screening Tool

- 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 (2)

- DT best measure; modification of problem checklist

- The DT and problem checklist (PCL) were developed for adult cancer populations and have only been validated in those populations. The cut-off used for the DT is based on studies with older patients.

- Further validation will lead to improvements

*Distress: “a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment.” (NCCN)
AYA DT Research Project Aims

Primary aim
The primary aim is the validation and clinical utility of the screening tool for AYA cancer patients; specifically, to determine appropriate cut-offs for clinical use, assess the clinical utility (appropriateness, practicability, and acceptability) of the tools, and confirm the content validity of the checklist.

Secondary aims
Secondary aims include: measuring prevalence and predictors (demographic, cancer, health literacy, family functioning, and spirituality variables) of distress; examining service responsiveness; and conducting international comparisons for prevalence, and predictors of distress and psychosocial concerns in AYA patients.
Cut-off value and PCL content

- To determine an appropriate cut-off value, comparisons are made between responses on existing validated measures and those on the DT
  - HADS and K10

- Content of the PCL will be evaluated by reviewing which items are selected and additional items raised by patients
Prevalence and predictors of distress*

This study will also enable prevalence of distress to be determined and variables impacting on distress levels.

Prevalence data and a representative sample.

Predictors:
- treatment status (Dyson et al., 2012)
- cancer type (Neville et al., 1996)
- age (Kim et al., 2013)
- involvement with school or work (Kwak et al., 2012)
- economic status (Kim et al., 2013)
- levels of support (Hatcher et al., 2012)
- health literacy (Koay et al., 2012; McDonald et al., 2012)
- spirituality (Visser et al., 2010)
- family functioning (Edwards et al., 2005)
Clinical utility*

- Examined from both patient and clinician perspectives

- Clinical utility framework (3)
  - Appropriateness – relevance and effectiveness of tool; fitting in to existing processes
  - Practicability – ease of instructions
  - Acceptability – satisfaction with the tool and process

Distress screening programs require three components to be effective (4)

1. use of a screening tool
2. triage to services
3. quality treatments

While this study will not be able to examine the quality of support and services AYAs are referred to directly, we will assess service responsiveness by examining responses to referrals and patient satisfaction.

International Considerations*

Distress screening for the AYA cancer population is being considered for implementation as standard practice internationally and there are benefits in developing a consistent international approach.