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A Systematic Review of the Psychosocial Measures Used in Teenage and Young Adult Cancer

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Abstract

Background

Teenagers and young adults (TYAs; ages 16-24 in the UK) with cancer have specific needs and experience worse physiological and psychological outcomes compared to paediatric and adult cancer. In the UK, psychosocial screening is a mandatory part of TYA care. However, there is a lack of age-appropriate and acceptable psychosocial measures for this population. This review aimed to (i) identify the psychosocial measures utilised and available for TYA cancer and (ii) describe their psychometric properties.

Methods

We searched five databases for studies meeting eligibility criteria. We extracted data relevant to the review and assessed study quality using the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) guidelines and the Hughes Quality Assessment Tool developed by the research team.

Results

We identified 40 studies which included 105 psychosocial measures. The main constructs measured were distress, depression, and anxiety. The TYA age range varied widely. Reporting of psychosocial measures and their psychometric properties was poor, and most measures were not validated or developed for TYA cancer populations.

Discussion

There is an urgent need for psychosocial measures that are designed for and validated in TYA cancer populations. Appropriate measures would enable clinicians to reliably identify and effectively support the psychosocial challenges faced by TYAs. The use of validated psychosocial measures enables earlier detection of difficulties, fosters patient-centred care, and is cost-effective since resources can be allocated to those most in need.

Introduction

The transition from childhood to adulthood is particularly difficult for teenagers and young adults (TYAs; ages 16-24 in the UK) due to physical, psychological, and financial challenges¹⁻³. This is a period when TYAs are developing a stable identity, exploring independence from their family, and making important decisions about their future⁴⁻⁶. A cancer diagnosis can impact normative development during this period and cause substantial distress during and after recovery^{7,8}. Cancer can cause loneliness and changes to the self-concept that may affect how TYAs cope with treatment^{9,10}. Treatment can interfere with day-to-day life due to fatigue, nausea, and a loss of confidence that arises from changes in appearance¹. The type and length of treatment can reduce resilience² while prolonged treatment can cause feelings of helplessness^{2,10} and can be detrimental to relationships, education, and employment^{11,12}.

TYAs with cancer have specific needs compared to paediatric and adult cancer and require specialist services specifically tailored to this age group^{1,7,13}. They experience more complex emotional and social challenges compared to other groups and require extra support in navigating finances, treatment options, and advocacy concerns^{6,8}. TYAs also have worse cancer survival rates compared to children and adults for several cancers including breast cancer compared to adult populations and acute lymphoblastic leukaemia compared to children¹⁴. This suggests the biology of some cancers differs in TYAs compared to paediatric and adult populations¹⁴.

The definition of TYA varies across countries, resulting in a lack of consistent research across the field^{12,15,16}. In the UK the TYA age range is defined as ages 16 to 24¹⁷, but elsewhere TYAs have been defined as 15 to 39¹⁸. Past research has shown that TYAs are less likely to be referred for psychological support compared to younger children¹³ and feel less involved in healthcare discussions¹¹. More research into TYA cancer is needed to improve treatment, increase awareness of psychosocial difficulties, and ensure TYAs have a voice in their care.

In recognition of these discrepancies in care and outcomes, The National Institute for Health and Care Excellence (NICE) in the UK has made specific recommendations for TYAs with cancer. These include the use of psychosocial measures to identify those at risk of

distress^{1,19} and access to appropriate psychological and social support^{20,21}. Psychosocial screening should form a standard of psychosocial care^{15,22-24}, but there have been challenges in implementing evidence-based screening²⁵ due to a lack of acceptable and appropriate psychosocial measures^{26,27}. All healthcare professionals can benefit from appropriate psychosocial measures to quickly identify TYAs at risk of emotional difficulties. Such measures should address a range of issues including treatment-related distress, relationships, and social issues^{11,15,16}, while also identifying resilience and coping resources to aid adjustment to cancer^{6,15,28}.

Past studies have used a range of terms to describe psychosocial screening, often using them interchangeably. 'Screening tools' are short assessments which aim to identify people with a construct of interest such as distress²⁹. 'Outcome measures' refer to instruments that capture the patient's function at baseline (sometimes called screening) and following a treatment or intervention³⁰. 'Patient-reported outcome measures' (PROMs) are self-administered questionnaires that directly assess a patient's health status³¹. Since outcome monitoring may be used as a long-term approach to screening²⁴, this review uses the term 'psychosocial measure' to encompass all forms of psychosocial screening.

In the UK, psychosocial screening is a mandatory part of TYA cancer care and is important for guiding interventions¹⁷. However, it is unclear what validated psychosocial measures are available in this age group and clinical population. The British Psychological Society recommends that psychosocial measures used in cancer should be validated with standardised norms³², and that clinicians should be aware of the psychometric properties and clinical utility of measures. However, in TYA cancer there is a lack of research into appropriate measures and their properties^{19,33}. Validating existing psychosocial measures could be one solution but new measures developed specifically for this group may also be needed¹⁹.

Review Aims

To address the lack of research into age-appropriate and acceptable psychosocial measures for TYA cancer, this review aimed to (1) identify the psychosocial measures utilised and available for TYAs with cancer and (2) describe their psychometric properties.

Method

This systematic review adhered to PRISMA guidelines³⁴ and was registered with PROSPERO (07/02/22; reg no. CRD42022297985)³⁵. We used the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) guidelines to extract psychometric properties and assess the quality of studies meeting COSMIN's inclusion criteria³⁶.

Data Sources

Searches were conducted on 6th April 2022 and updated on 12th May 2023 on five databases: OVID MEDLINE, OVID Embase, OVID PsychInfo, EBSCO CINAHL, and Web of Science.

Search Terms and Strategy

Using the Patient, Intervention, Comparison, Outcome (PICO) framework³⁷ the main concepts identified were cancer, teenagers and young adults, and psychosocial measures. The keywords and subject headings are listed in Table 1. Each main concept was searched together using AND. No restrictions were set for publication date, peer reviewed publications, dissertations, or poster/conference abstracts. No language restrictions were set at initial search.

After removing duplicates, identified papers were screened by the author (KH) based on title and abstract. A second reviewer (LB) independently screened 20% of papers, also based on title and abstract, to check criteria were being followed objectively. All papers screened by LB were randomly selected. Initial agreement about eligible papers between the two reviewers was 99% based on titles and abstracts and 100% following discussions. Papers were excluded based on the criteria below. Full texts were screened by KH using the criteria below and 20% of these texts were screened by LB. Initial agreement was 90% for the full texts and 100% following discussions.

Inclusion/Exclusion Criteria

Studies were included or excluded if they met the criteria shown in Table 2.

COSMIN guidelines include the following eligibility criteria for systematic reviews of psychosocial measures³⁶:

- Measures should measure the construct of interest, in this case, psychosocial difficulties such as distress, anxiety, or depression.
- The study sample should represent the population of interest, in this case TYA cancer.
- The study should concern psychosocial measures.
- The study's aim should be to evaluate psychometric properties or to develop a measure.

However, as our primary aim was to identify which psychosocial measures are used in TYA cancer, we purposefully included studies only using psychosocial measures and not developing or evaluating them. Therefore, it was not possible to comply with COSMIN's guidelines for all studies.

Data Extraction

We extracted data based on COSMIN guidelines, past reviews, and discussions with clinicians. Data were extracted from all included papers by KH and 20% of data extraction was repeated by LB. Agreement was reached on 100% of the data extracted. See Supplement A for full details of what the data extraction table included.

Some studies in this review included multiple measures, meaning there were more measures than studies.

Psychometric properties for papers that were suitable for COSMIN evaluation

COSMIN can be used as a modular tool, so we only included sections that were relevant for our review³⁶. For papers meeting COSMIN eligibility criteria, we extracted structural validity, internal consistency, cross-cultural validity/measurement invariance, and reliability (see Supplement A, Table 1 for definitions of each property). We also collected information on criterion validity, however, there were no identified gold standard psychosocial measures in

this population (required for COSMIN assessment of criterion validity) and therefore this information is presented in Supplement A, Table 2 but does not form part of the main quality assessment.

These properties were rated using COSMIN criteria for good measurement properties³⁶ as sufficient (+), insufficient (-), or indeterminate (?). COSMIN recommends pooling findings together to identify the most suitable measure. However, this was not possible due to the small number of measures identified and the wide range of constructs covered.

Psychometric properties for measures that did not meet COSMIN eligibility criteria

For measures not meeting COSMIN criteria, we searched the full texts for the following psychometric properties: internal consistency, test-retest reliability, construct validity, sensitivity, and specificity. To ease comparison, we grouped these measures as (i) non-cancer populations; (ii) cancer populations but not specific to TYA; and (iii) TYA cancer populations.

We used narrative synthesis to summarise these psychosocial measures and their psychometric properties. The approach involved summarising the findings from the different studies based on the use of words, text, and reported psychometric properties.

Quality Assessment

All papers retained after screening were assessed by KH using either the COSMIN risk of bias checklist³⁸ or a quality assessment tool developed by the research team (Hughes Quality Assessment Tool, described below). 50% of these papers were also assessed by LB and final agreement was reached on 100% of papers.

COSMIN risk of bias checklist³⁸

The COSMIN risk of bias checklist was used to assess the quality of studies meeting COSMIN eligibility criteria. This checklist was used as a modular tool and further information about the tool can be found in Supplement A.

The methodological quality of each section was rated as very good, adequate, doubtful, or inadequate based on COMSIN criteria. Overall ratings of each section were given the lowest

rating of any criteria within that domain i.e. “worst score counts”³⁶. Since the aim of this review was to identify the psychosocial measures utilised and available in TYA cancer, all studies were included, regardless of quality.

Hughes Quality Assessment Tool

For papers that could not be quality-assessed using the COSMIN risk of bias checklist, we used an alternative quality assessment tool created by the research team. This tool was guided by criteria created to review health status and quality of life tools³⁹ and assessed (i) the conceptual and measurement model; (ii) reliability and validity; (iii) interpretability; (iv) mode of administration; and (v) cultural or language adaptations (see Supplement A for details).

Results

Aim 1: Identify the psychosocial measures utilised and available for TYAs with cancer

Overview of studies

From five databases we identified 1126 papers after the removal of duplicates (Figure 1). 1020 papers were excluded based on title and abstract screening mostly due to the papers not being about TYAs or being about an illness other than cancer. Of the remaining 106 papers, full texts were retrieved for 60 papers. We were unable to retrieve full texts for 46/106 papers, despite contacting all corresponding authors who had shared their email to request full texts. Many of the full texts could not be retrieved as they were conference or poster abstracts (n=40). Of the 60 papers retrieved, 20/60 were excluded as they did not meet the eligibility criteria for this review. Excluded papers were those addressing measures for TYA cancer survivors (n=3); not mentioning a measure (n=8); not defining a TYA age range (n=4); study protocol (n=1); not providing any details about the measure (n=2); combined TYA cancer with chronic illness (n=1); not written in English (n=1). 40 studies were therefore included in this review.

Study and measure characteristics

The 40 studies were carried out in 12 countries. These countries were predominantly the USA (n=10 studies), Canada (n=7), China (n=4), Germany (n=3), Australia (n=4), UK (n=2), Japan (n=2), India (n=2), and Singapore (n=2). One study was carried out across 4 countries (Australia, Canada, UK, and USA). The remaining studies were carried out in a single country (see Supplement A, Table 3). 33/40 studies were carried out in a research setting and 7/40 in a clinical setting. TYA ages ranged from 11-45, and the most commonly-reported age ranges were 15-39 (n=15) and 18-39 (n=11). The UK definition of TYAs aged 16-24 was used in only 1 study. Most studies covered a wide range of cancer diagnoses, but 2 focused on breast cancer only and 1 on germ cell tumours only.

We identified 105 measures across the 40 studies, since some studies included multiple measures (see Table 3). We identified measures in 8 languages; predominantly English (n=25 studies), Chinese (n=4) and German (n=3). 53/105 (50%) measures were screening tools, 25/105 (24%) were outcomes, 16/105 (15%) were validation tools, 8/105 (8%) were predictors, 2/105 (2%) were outcomes and predictors, and 1/105 (1%) was a covariate. 41/105 (39%) measures were self-report with no mode of administration mentioned, 22/105 (21%) were paper self-report, 18/105 (17%) were paper or electronic self-report, 17/105 (16%) were electronic self-report, 3/105 (3%) were face-to-face interviews, 2/105 (2%) were not stated and 2/105 (2%) were not applicable as the paper focused on a discussion around the development of the measure.

The main constructs measured were distress (31/105 measures, 30%), depression (19/105, 18%), anxiety (16/105, 15%), quality of life (9/105, 9%), social support (6/105, 6%), psychosocial health/functioning (5/105, 5%), symptom burden (3/105, 3%) and medical coping (3/105, 3%). Despite distress being the most commonly-measured construct, it was clearly defined in only two papers^{40,41} as an unpleasant emotional experience which can be psychological, social or emotional, and can range from feelings of sadness to clinical symptoms of psychological difficulties. The most commonly-reported measures were: Distress Thermometer with associated problem/concern checklist (12/105 measures, 11%); Hospital Anxiety and Depression Scale (9/105, 9%); Patient Health Questionnaire in various forms e.g. PHQ-9, PHQ-8, PHQ-2 (6/105, 6%); Distress Thermometer only (5/105, 5%);

Kessler Psychological Distress Scale- 10 and 6 (4/105, 4%); Generalised Anxiety Disorder Scale-7 (4/105, 4%); Canadian Problem Checklist (3/105, 3%); Paediatric Quality of Life Inventory (3/105, 3%); Cancer Distress Scales for Adolescents and Young Adults (3/105, 3%); and the PsychoSocial Screen for CANcer-Revised (3/105, 3%).

Quality Assessments

74/105 measures were assessed using the Hughes Quality Assessment Tool (see Supplement A, Table 4) and 15/105 were assessed using the COSMIN Risk of Bias Checklist³⁸ (see Supplement A, Table 5). The remaining 16/105 measures were validation tools and were therefore not quality assessed.

Hughes Quality Assessment Tool

Conceptual and measurement model

The concept being measured was fully defined in 72/74 (97%) measures and partially defined in 2/74 (3%). The population that the measure was validated in was adequately described in 29/74(39%) measures, partially described in 21/74 (28%) and not described in 24/74 (32%). The measure was validated in a TYA cancer population for 13/74 (18%) measures.

Reliability

Reliability was reported for 29/74 (39%) measures. Internal consistency was reported for 18/74 (24%) measures with 14/74 (19%) reporting a statistic. Test-retest reliability was reported for 2/74 (3%) measures with none reporting a statistic. Where no statistic was reported a statement such as 'good test-retest reliability' was stated.

Validity

Validity was reported for 39/74 (53%) measures. 3/74 (4%) reported on construct validity specifically but gave no statistic and 2/74 (3%) reported on convergent validity but again gave no statistic.

Interpretability

Very clear explanations of how to interpret scores was given for 35/74 (47%) measures, 29/74 (39%) were partially clear, 6/74 (8%) were not clear, and 4/74 (5%) were not stated. Cut-offs were reported for 33/74 (45%) measures.

Method of administration

The method of administration was reported for 61/74 (82%) measures which was predominantly self-report (39 measures), paper self-report (16) and online self-report (11).

Cultural and language adaptations

23/74 (31%) measures were translated into another language and the psychometric properties were evaluated for 10 of these measures.

COSMIN Risk of Bias Checklist

15/105 measures were rated using this checklist.

PROM development

The development of 6/15 (40%) measures was reported; 4 were rated as inadequate and 2 were doubtful.

Content validity

Patients were asked about the relevance, comprehensiveness, and comprehensibility for 5/15 (33%) measures with the majority of methodologies being rated as doubtful except McGrady et al. 2022⁴² which had comprehensiveness and comprehensibility rated as adequate and Patterson et al. 2022⁴³ which had all areas rated as adequate. Professionals were asked about relevance for 8/15 (53%) measures and comprehensiveness for 3/15 (20%). All were rated as doubtful except for Patterson et al. 2022⁴³ which was rated as adequate.

Structural validity

Structural validity was reported for 4/15 (27%) measures; 3 were rated as very good and 1 as inadequate.

Internal consistency

Internal consistency was reported for 7/15 (47%) measures and all were rated as very good.

Cross-cultural validity

Cross-cultural validity was reported for 5/15 (33%) measures with 4 rated as inadequate and 1 as doubtful.

Reliability

Reliability was reported for 8/15 (53%) measures with 4 rated as inadequate and 4 as doubtful.

Measurement error

Measurement error was not reported for any measures.

Construct validity

Convergent validity was reported for 11/15 (73%) measures; 6 were rated as adequate, 4 as doubtful and 1 as inadequate. Discriminative or known group validity was reported for 7/15 (47%) measures with 2 rated as very good and 5 as doubtful.

Responsiveness

11/15 (73%) measures were compared with other instruments. 6 were rated as adequate, 4 as doubtful and 1 as inadequate. 7/15 (47%) measures were compared between subgroups; 5 were rated as doubtful and 2 as very good. 5/15 (33%) measures were compared before and after an intervention and all were rated as doubtful.

Aim 2: Describe the psychometric properties of these measures

Of the identified measures, only 45/105 reported psychometric properties and are therefore included in this section. 15/105 were rated using COSMIN guidelines to describe their psychometric properties. 30/105 measures reported psychometric properties but were not rated using COSMIN guidelines; 8 of these measures were validated in non-cancer populations, 7 were validated in cancer populations, and 15 were validated in TYA cancer populations.

Measures rated using COSMIN guidelines (15/105)

The psychometric properties of these measures were rated against the criteria for good measurement properties as stated in COSMIN guidelines and full details of the reported properties can be found in Supplement A, Table 6.

Structural validity

Structural validity was reported for 4/15 (27%) measures. All measures were rated as insufficient as they did not report adequate goodness-of-fit statistics except for 1 measure which was rated as sufficient.

Internal consistency

Internal consistency was reported for 7/15 (47%) measures, with 6 rated as sufficient (Cronbach alpha or Omega ≥ 0.70) and 1 as insufficient (Cronbach alpha or Omega < 0.70).

Cross-cultural validity/measurement invariance

Cross-cultural validity/measurement invariance was reported for 5/15 (33%) measures with 4 rated as indeterminate and 1 as adequate. 4 were indeterminate as they did not carry out multiple group factor analysis or differential item functioning. 1 was only adequate as there was no important differential item functioning for group factors.

Reliability

Reliability was reported for 9/15 (60%) measures with 6 rated as sufficient and 3 as insufficient. Measures were rated as sufficient if they had an intraclass correlation coefficient (ICC) of greater than or equal to 0.70.

Measures that were not rated using COSMIN guidelines (30/105)

Psychometric properties were extracted for the remaining measures and full details are reported in Supplement A, Tables 7-9.

Psychometric properties were reported for 8 measures that were validated in non-cancer populations:

Internal consistency (Cronbach alpha) was reported for 7/8 (88%) measures and ranged from 0.67-0.94. Test-retest reliability (ICC) and construct validity (mean diff [Standard Error]) were reported for 1/8 (13%) measures and sensitivity/specificity was reported for 1/8 (13%) measures.

Psychometric properties were reported for 7 measures that were validated in cancer populations but were not specific TYA cancer populations:

Internal consistency (Cronbach alpha) was reported for 4/7 (57%) measures and ranged from 0.82-0.9. Test-retest reliability (ICC) was reported for 2/7 (29%) measures and ranged from 0.73-0.84. Construct validity (mean diff [SE]) was reported for 2/7 (29%) measures and sensitivity/specificity was reported for 2/7 (29%) measures.

Psychometric properties were reported for 15 measures that were validated in TYA cancer populations:

Internal consistency (Cronbach alpha) was reported for 11/15 (73%) measures and ranged from 0.56-0.96 while sensitivity/specificity was reported for 5/15 (33%) measures.

Discussion

This systematic review found 105 psychosocial measures used in TYA cancer populations in 40 studies carried out across 12 countries. Most measures were used in a research setting, covered a wide range of cancer diagnoses, were self-report, and were predominantly

written in English. The reported age ranges varied widely, with the most commonly reported ages 15-39 and 18-39. Only one study met the UK definition of TYA (ages 16-24). The most commonly-measured constructs were distress, depression, and anxiety, and the most commonly-reported measure was the Distress Thermometer with associated problem/concern checklist. Very few measures were developed (6/105, 6%) and/or validated (28/105, 27%) in a TYA cancer population. Studies were generally of poor quality due to the lack of validation in TYA cancer, poor testing or reporting of psychometric properties, and where psychometric properties were reported, the methods used were often doubtful or insufficient.

Previous research has shown that TYAs with cancer are at increased risk of distress, depression, and anxiety which can have an impact on pain, length of hospital admission and treatment adherence^{44,45}. It was therefore predictable that the most commonly-measured constructs in this review were distress, depression, and anxiety and that the Distress Thermometer with associated problem/concern checklist was the most frequently-reported measure. However, distress was only defined in two studies^{40,41}, meaning the construct being measured was unclear and there were possible overlaps with depression and anxiety⁴⁵. The Distress Thermometer is frequently used in adult cancer although there have been criticisms that this single-item measure could over-estimate levels of distress⁴⁶. Using the Distress Thermometer with an associated problem/concern checklist may address this criticism.

No measures were developed for a specific cancer diagnosis or treatment type, and only three studies focused on a single type of cancer. Given the large variation in the physiological and psychological impacts of different diagnoses and treatments², it would be beneficial to explore whether measures' psychometric properties are stable across multiple diagnoses and treatments. Future research should focus on validating psychosocial measures for specific diagnoses and treatment types to address this gap in the literature.

Wide variations in the TYA age range across studies and countries highlight the lack of consistency in classifying this group. From a physiological and developmental perspective, those in their late adolescence and early twenties have very different needs from those in their thirties^{47,48}; measures developed and validated in TYAs aged 18-39 might be

inappropriate for those aged 16-24. Consistency across TYA cancer research is required to understand the needs of this group, create appropriate measures, and develop suitable interventions. It has also been suggested that presenting validation data for subgroups of TYAs (for example those aged 16-18 and 18-24) could help manage the challenges around defining this age group^{19,47}.

Most studies in this review were conducted in a research setting (33/40) rather than a clinical setting (7/40). Therefore, the reported psychosocial measures provide little insight into which measures are used in clinical setting. This suggests that increased reporting of screening tools in clinical settings is needed. For example, future research should employ alternative methods (e.g. directly surveying clinicians) to better understand which measures are used in clinical practice and their reliability and validity for the TYA population.

The reporting of psychometric properties was almost universally poor. Previous research into adult and paediatric cancer has also highlighted poor reporting of psychometric properties^{49,50} suggesting that something that has been overlooked more broadly across the cancer field. Very few measures were developed and validated in TYA cancer populations. For clinicians to be confident that measures are reliably capturing the constructs they purport to, it is crucial for studies to report psychometric properties to identify measures with acceptable validity, reliability, and sensitivity^{19,46}. It is also important for cross-cultural validity to be explored given TYAs with cancer are from diverse backgrounds, and culture can influence coping strategies and treatment adherence⁵¹. Although our review was restricted to publications written in English, and therefore found most measures were written in English, it is vital for psychosocial measures to be translated and validated in a range of languages to ensure they are culturally sensitive and inclusive for all.

Our findings suggest several recommendations for future studies in TYA cancer. First, a consistent age range should be agreed upon, and psychosocial measures should be developed and validated for this age group. Second, psychosocial measures should be specifically tailored for this age group to include relevant issues such as education, work, and finances. Third, given the variability across cancers, it will be important to develop and validate psychosocial measures for specific diagnoses and treatment types. However, when screening for specific conditions such as anxiety or depression, it will still be necessary for

psychosocial measures to meet certain standards, such as those based on ICD-11⁵² and DSM-V⁵³ criteria, that are consistent across all ages and cancer diagnoses and treatments. Finally, validation studies must consistently report psychometric properties and clinical thresholds. This will enable clinicians to use appropriate, validated scales to identify TYAs requiring further assessment and to allocate psychosocial interventions to those most in need.

Strengths and limitations

This was the first study to comprehensively review the psychosocial measures utilised and available in TYA cancer. We assessed the quality and psychometric properties of the included studies and measures. While most studies were rated as poor quality, this review provides clear guidance for future research to address this significant gap in TYA cancer care.

In terms of limitations, we restricted our review to published studies written in English, excluding measures reported in grey literature or published in another language. Secondly, the gold standard for assessing the methodology and reporting psychometric properties of measures would be to follow COSMIN guidelines³⁶. However, given that the main aim of this review was to identify the psychosocial measures utilised and available TYA cancer, these guidelines could not be followed for all studies as they did not solely focus on the development or psychometric properties of measures in this population. The research team therefore developed a quality assessment tool that was appropriate for the studies included in this review that did not meet COSMIN's inclusion criteria, but this tool has not been peer reviewed. It was thus challenging to draw common themes around methodological quality. Additionally, a large proportion of the measures included were not validated in TYA cancer populations.

Conclusion

The use of psychosocial measures throughout cancer diagnosis and treatment can lead to early detection of mental health difficulties, which allows for proactive rather than reactive interventions^{46,54}. Regular psychosocial screening at key intervals from cancer diagnosis to follow-up/bereavement could identify those in need of support, distribute resources

effectively, and tailor interventions appropriately^{20,48}. This systematic review identified a number of psychosocial measures available for TYAs with cancer which predominantly measured distress, depression, and anxiety. However, there was wide variation in the TYA age range and types of cancer, both within and between studies. Most measures were not validated in a TYA cancer population and reporting of psychometric properties was poor. This review highlights a crucial need for measures to be validated specifically in TYA cancer populations if we are to reliably screen for, and support effectively, distress in young people with cancer.

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Author Contribution Statements

KH was involved in the review's conceptualisation, database searches, screening, data extraction, quality assessments, and write-up.

LB was involved in screening, data extraction, and quality assessments.

EC, SH, CJ provided supervision and guidance for the review's conceptualisation, analysis, and write-up.

Author Disclosure

A paper written by CJ was included in this review however, only KH and LB were involved in the assessment of this paper.

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References

1. Adloff K. A pilot study of a psychosocial assessment tool for young adults with cancer. *Diss Abstr Int* 2010;70(10-B):6536.
2. Evan EE, Zeltzer LK. Psychosocial dimensions of cancer in adolescents and young adults. *Cancer* 2006;107(S7):1663-1671.
3. McNeil RJ, McCarthy M, Dunt D, et al. Financial challenges of cancer for adolescents and young adults and their parent caregivers. *Soc Work Res* 2019;43(1):17-30.
4. Smrke A, Leung B, Bates A, et al. Psychosocial distress of adolescent and young adults with cancer at diagnosis: A case-matched retrospective cohort of 2045 patients in British Columbia. *Ann Oncol* 2019;30(v735-v736).
5. D'Agostino NM, Penney A, Zebrack B. Providing developmentally appropriate psychosocial care to adolescent and young adult cancer survivors. *Cancer* 2011;117(10 Suppl):2329-34; doi:10.1002/cncr.26043.
6. Zebrack B, Isaacson S. Psychosocial care of adolescent and young adult patients with cancer and survivors. *J Clin Oncol* 2012;30(11):1221-1226.
7. Anazodo A, Chard J. Medical and psychosocial challenges in caring for adolescent and young adult patients with cancer. *Cancer Forum* 2013;37(1):23-26.
8. Folbrecht J, Mayorga L, Cabanillas C, et al. Psychosocial services utilized by older adolescents and young adults at a comprehensive cancer center. *Asia Pac J Clin Oncol* 2012;8(SUPPL. 3):262; doi:<http://dx.doi.org/10.1111/ajco.12030>.
9. Bertolotti M, Massaglia P. Psycho-oncology in childhood and adolescence: The Italian experience. *Neuropathol Dis* 2012;1(1):71-93; doi:<http://dx.doi.org/10.1615/NeuropatholDiseases.v1.i1.50>.
10. Blotcky AD, Cohen DG. Psychological assessment of the adolescent with cancer. *J Assoc Pediatr Oncol Nurses* 1985;2(1):8-14.
11. Sawyer S, McNeil R, Thompson K, et al. Developmentally appropriate care for adolescents and young adults with cancer: how well is Australia doing? *Support Care Cancer* 2019;27(5):1783-1792.
12. Seitz DC, Besier T, Goldbeck L. Psychosocial interventions for adolescent cancer patients: a systematic review of the literature. *Psychooncology* 2009;18(7):683-690.
13. Clerici CA, Massimino M, Casanova M, et al. Psychological referral and consultation for adolescents and young adults with cancer treated at pediatric oncology unit. *Pediatr Blood Cancer* 2008;51(1):105-109; doi:<http://dx.doi.org/10.1002/pbc.21484>.

14. Keegan TH, Ries LA, Barr RD, et al. Comparison of cancer survival trends in the United States of adolescents and young adults with those in children and older adults. *Cancer* 2016;122(7):1009-1016.
15. Bradford N, Cashion C, Holland L, et al. Coping with cancer: A qualitative study of adolescent and young adult perspectives. *Patient Educ Couns* 2022;105(4):974-981; doi:<https://dx.doi.org/10.1016/j.pec.2021.07.034>.
16. Coccia PF, Pappo AS, Beaupin L, et al. Adolescent and young adult oncology, version 2.2018, NCCN clinical practice guidelines in oncology. *J Natl Compr Canc Netw* 2018;16(1):66-97.
17. NHS England. NHS Cancer Services for Teenagers and Young Adults. 2015.
18. National Cancer Institute. Adolescents and Young Adults with Cancer. 2023. Available from: <https://www.cancer.gov/types/aya> [Last Accessed; 19/05/23].
19. Wakefield CE, Patterson P, McDonald FE, et al. Assessment of psychosocial outcomes in adolescents and young adults with cancer: a systematic review of available instruments. 2013;
20. NICE. Cancer services for children and young people. 2014.
21. NHS England. Service Specifications for TYA Principal Treatment Centres and Networks.
22. Barrera M, Young MA, Hancock K, et al. Early trajectory of psychosocial risk in families of children and adolescents newly diagnosed with cancer. *Support Care Cancer* 2022;30(2):1815-1822; doi:<https://dx.doi.org/10.1007/s00520-021-06581-3>.
23. Patterson P, Allison KR, Bibby H, et al. The Australian Youth Cancer Service: developing and monitoring the activity of nationally coordinated adolescent and young adult cancer care. *Cancers* 2021;13(11):2675.
24. Kazak AE, Abrams AN, Banks J, et al. Psychosocial assessment as a standard of care in pediatric cancer. *Pediatr Blood Cancer* 2015;62(S5):S426-S459.
25. Marchak JG. Implementation of electronic psychosocial screening among AYAs with cancer. *Psychooncology* 2021;30(SUPPL 1):23; doi:<https://dx.doi.org/10.1002/pon.5637>.
26. McGrady M. "Behind the Scenes" in measure development: Engaging stakeholders to develop a psychosocial assessment strategy for young adults with cancer. *Psychooncology* 2021;30(SUPPL 1):24; doi:<https://dx.doi.org/10.1002/pon.5637>.
27. Patterson P. Assessing and managing the distress and psychosocial needs of AYA cancer patients. *Psychooncology* 2015;24(SUPPL. 2):40-41; doi:<http://dx.doi.org/10.1002/pon.3873>.
28. Patterson P, Hardman F, Cheshire J, et al. Balancing risk with resilience: Using holistic psychosocial screening and assessment tools effectively with adolescents and young adults

- with cancer. In: *Nursing Adolescents and Young Adults with Cancer*. Springer: 2018; pp. 95-119.
29. National Comprehensive Cancer Network. Distress during cancer care. 2020. Available from: <https://www.nccn.org/patients/guidelines/content/PDF/distress-patient.pdf> [Last Accessed; 19/05/2023].
 30. Maldonado E, Thalla N, Nepaul S, et al. Outcome measures in cancer rehabilitation: pain, function, and symptom assessment. *Front Pain Res* 2021;54.
 31. Prinsen CA, Mokkink LB, Bouter LM, et al. COSMIN guideline for systematic reviews of patient-reported outcome measures. *Qual Life Res* 2018;27(1147-1157).
 32. The British Psychological Society. *Demonstrating Quality and Outcomes in Psycho-oncology*. 2015.
 33. Yardeni M, Abebe Campino G, Bursztyn S, et al. A three-tier process for screening depression and anxiety among children and adolescents with cancer. *Psychooncology* 2020;29(12):2019-2027; doi:<http://dx.doi.org/10.1002/pon.5494>.
 34. PRISMA. Transparent reporting of systematic reviews and meta-analyses. 2020. Available from: <https://www.prisma-statement.org/> [Last Accessed; 14/12/22].
 35. PROSPERO. International prospective register of systematic reviews. Available from: <https://www.crd.york.ac.uk/prospero/> [Last Accessed; 14/12/22].
 36. COSMIN. COSMIN methodology for systematic reviews of Patient-Reported Outcome Measures (PROMs). 2018. Available from: https://www.cosmin.nl/wp-content/uploads/COSMIN-syst-review-for-PROMs-manual_version-1_feb-2018-1.pdf [Last Accessed; 14/12/22].
 37. Eriksen MB, Frandsen TF. The impact of patient, intervention, comparison, outcome (PICO) as a search strategy tool on literature search quality: a systematic review. *J Med Libr Assoc* 2018;106(4):420.
 38. COSMIN. COSMIN Risk of Bias checklist. 2018. Available from: https://www.cosmin.nl/wp-content/uploads/COSMIN-RoB-checklist-V2-0-v17_rev3.pdf [Last Accessed; 14/12/22].
 39. Lohr KN. Assessing health status and quality-of-life instruments: attributes and review criteria. *Qual Life Res* 2002;11(3):193-205.
 40. Rae C, Klassen AF, Tsangaris E, et al. Distress Screening in Adolescents and Young Adults with Cancer: Development of Cut-Points for the Cancer Distress Scales-Adolescent and Young Adults. *Journal of adolescent and young adult oncology* 2019;8(5):560-565; doi:<https://dx.doi.org/10.1089/jayao.2019.0032>.

41. Burgoyne MJ, Bingen K, Leuck J, et al. Cancer-Related Distress in Young Adults Compared to Middle-Aged and Senior Adults. *J Adolesc Young Adult Oncol* 2015;4(2):56-63; doi:<https://dx.doi.org/10.1089/jayao.2014.0005>.
42. McGrady ME, Mara CA, Beal SJ, et al. Development and Preliminary Validation of a Multidimensional Psychosocial Assessment Strategy for Young Adults With Cancer. *J Pediatr Psychol* 2022; doi:<https://dx.doi.org/10.1093/jpepsy/jsac032>.
43. Patterson P, McDonald FEJ, Allison KR, et al. The Clinical Utility of the Adolescent and Young Adult Psycho-Oncology Screening Tool (AYA-POST): Perspectives of AYA Cancer Patients and Healthcare Professionals. *Front Psychol* 2022;13(872830); doi:<https://dx.doi.org/10.3389/fpsyg.2022.872830>.
44. Lang MJ, David V, Giese-Davis J. The age conundrum: a scoping review of younger age or adolescent and young adult as a risk factor for clinical distress, depression, or anxiety in cancer. *J Adolesc Young Adult Oncol* 2015;4(4):157-173.
45. Lauer AL. Treatment of anxiety and depression in adolescents and young adults with cancer. *J Pediatr Oncol Nurs* 2015;32(5):278-283.
46. Zabora JR, MacMurray L. The history of psychosocial screening among cancer patients. *J Psychosoc Oncol* 2012;30(6):625-635.
47. Aubin S, Barr R, Rogers P, et al. What should the age range be for AYA oncology? *J Adolesc Young Adult Oncol* 2011;1(1):3-10.
48. Richter D, Koehler M, Friedrich M, et al. Psychosocial interventions for adolescents and young adult cancer patients: a systematic review and meta-analysis. *Crit Rev Oncol Hematol* 2015;95(3):370-386.
49. Vodermaier A, Linden W, Siu C. Screening for emotional distress in cancer patients: a systematic review of assessment instruments. *J Natl Cancer Inst* 2009;101(21):1464-1488.
50. Solans M, Pane S, Estrada MD, et al. Health-related quality of life measurement in children and adolescents: a systematic review of generic and disease-specific instruments. *Value Health* 2008;11(4):742-764.
51. Grassi L, Caruso R, Sabato S, et al. Psychosocial screening and assessment in oncology and palliative care settings. *Front Psychol* 2015;5(1485).
52. International Classification of Diseases 11th Revision. International Statistical Classification of Diseases and Related Health Problems (ICD). 2022. Available from: <https://www.who.int/standards/classifications/classification-of-diseases> [Last Accessed; 22/05/23].
53. American Psychological Association. Diagnostic and statistical manual of mental disorders (5th ed.). 2013; doi:<https://doi.org/10.1176/appi.books.9780890425596>.

54. Pearce S. Policy and practice in teenage and young adult cancer care in England: looking to the future. *Eur J Oncol Nurs* 2009;13(3):149-153.

Table 1. Search Terms

	Main concepts	Alternative keywords	Subject headings
P	Cancer	cancer OR oncol* OR tumor* OR tumour* OR neoplasm* OR malignan*	Neoplasms (OVID MEDLINE/PsychInfo/EBSCO CINAHL) Malignant neoplasm (OVID Embase)
P	Teenagers and young adults	teen* OR "young adult*" OR "young person" OR "young people*" OR adolescen*	Adolescence (OVID MEDLINE/EBSCO CINAHL) Adolescent (OVID Embase) Young Adults (OVID MEDLINE/Embase/EBSCO CINAHL)
I	Psychosocial measures	"psycho* screen*" OR "distress* screen*" OR "psycho* assess*" OR "distress* assess*" OR "psycho* instrument*" OR PHQ OR "patient history questionnaire" OR GAD-7 OR "generalised anxiety disorder assessment" OR "distress thermometer" OR "cognitive screen*"	Mental health screening (EBSCO CINAHL)

Table 2. Inclusion and Exclusion Criteria

Inclusion Criteria	<ul style="list-style-type: none">• Age group defined as adolescent or teenage or young adult. The definition of this group varies widely so no numeric age range was set. Actual age range was reported in the results.• Diagnosis of cancer.• Publications written in English.• Psychosocial measures were utilised or developed in the study.
Exclusion Criteria	<ul style="list-style-type: none">• Paediatric or adult cancer (as above, no specific age range was set).• Diagnosis other than cancer.• Publications not written in English.• Studies using psychosocial measures in TYA cancer survivors (i.e. studies where the participants were beyond the diagnosis and treatment stage).

Table 3. Overview of Studies and Measures

		Clinical				Research				
		N studies (N measures)				N studies (N measures)				
		18-39	15-39	15-25	16-24	18-39	15-39	15-25	16-24	Other
Country	USA	4(5)				1(6)	2(4)			3(5)
	Canada	3(7)				1(2)	3(10)			
	China						4(15)			
	Germany					2(5)	1(2)			
	Australia							3(11)	1(2)	
	UK									2(10)
	Singapore						2(6)			
	Other						3(3)			5(12)

Figure 1. PRISMA flow chart of search results

