The Association of Resilience with Psychosocial Outcomes in Teenagers and Young Adults with Cancer

Hughes, Katie

Awarding institution:
King's College London

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Systematic Literature Review

Empirical Project

Kathryn Hughes

Supervised by Dr Susie Henley, Dr Ewan Carr, & Dr Clare Jacobson

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Institute of Psychiatry, Psychology and Neuroscience

King's College London

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Contribution Statements

Systematic Literature Review: I was involved in the review's conceptualisation and conducted the database searches, screening, data extraction, and quality assessment. I developed the Hughes Quality Assessment Tool and wrote the review. Laura Blackett was the second reviewer for the screening, data extraction, and quality assessment. Dr Clare Jacobson provided supervision and guidance for the review's conceptualisation and write-up. Dr Susie Henley and Dr Ewan Carr provided supervision and guidance for the review's conceptualisation, analysis, and write-up.

Empirical Project Part 1: I was involved in the study conceptualisation as I selected the variables to use in this research and formulated the overarching research aims. I extracted data from patient records, cleaned the data from IMPARTS, selected the statistical method, conducted the formal analysis, and wrote the paper. Dr Clare Jacobson supervised the study conceptualisation and write-up. Dr Susie Henley and Dr Ewan Carr provided supervision and guidance for the study conceptualisation, formal analysis, and write-up. IMPARTS supported the ethical approval process and data collection.

Empirical Project Part 2: I was involved in the study conceptualisation as I formulated the overarching research aims. I extracted data from patient records, cleaned the data from IMPARTS, conducted the formal analysis, and wrote the paper. Dr Clare Jacobson supervised the study conceptualisation. Dr Susie Henley provided supervision and guidance for the study conceptualisation, the variables to focus on, the formal analysis, and write-up. Dr Ewan Carr provided supervision and guidance for the study conceptualisation, the statistical methods, the formal analysis, and write-up. IMPARTS supported the ethical approval process and data collection.

Overview of Contents

Chapter 1

Systematic Literature Review

A Systematic Review of the Psychosocial Screening Tools used in Teenage and Young Adult Cancer

Supervised by Dr Susie Henley, Dr Ewan Carr, & Dr Clare Jacobson

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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 screening tools for this population. This review aimed to (i) identify the psychosocial screening tools 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 35 studies which included 97 screening tools. The main constructs measured were distress, depression, and anxiety. The TYA age range varied widely. Reporting of screening tools and their psychometric properties was poor, and most tools were not validated or developed for TYA cancer populations.

Discussion

There is an urgent need for screening tools that are designed for and validated in TYA cancer populations. Appropriate tools would enable clinicians to reliably identify and effectively support the psychosocial challenges faced by TYAs. The use of validated psychosocial screening tools 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 challenges[1-3]. This is a period when TYAs are developing a stable identity, exploring independence from their family, and making important decisions about their future[4-6]. 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 appearance[1]. The type and length of treatment can reduce resilience[2] 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 service provision[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[14].

The definition of TYA varies across countries, meaning there is a lack of consistent research across the field[12,14,15]. In the UK the TYA age range is defined as ages 16 to 24[16], but elsewhere TYAs have been defined as 15 to 39 or 18 to 39[17,18]. Past research has shown that TYAs are less likely to be referred for psychological support compared to younger children[13] and feel less involved in healthcare discussions[11]. 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 screening tools 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[15,22,23], but there have been challenges

in implementing evidenced-based screening[24] due to a lack of acceptable and appropriate psychosocial screening tools[25,26]. All healthcare professionals can benefit from appropriate psychosocial screening tools to quickly identify TYAs at risk of emotional difficulties. Such tools should address a range of issues including treatment-related distress, relationships, and social issues[11,14,15] while also identifying resilience and coping resources to aid adjustment to cancer[6,15,27].

TYAs have specific needs and experience worse medical and psychological outcomes compared to paediatric and adult cancer[1]. Psychosocial screening can help our understanding of the impact of cancer on the development of TYAs[28]. It allows psychological interventions to be targeted to those most in need, informs the level of support required, and allows effective resource distribution[1,15,27]. TYAs who do not receive timely or appropriate psychosocial support have lower treatment adherence and more difficulties adjusting to their diagnosis[1,7]. TYAs with cancer are less likely to use mental health services and find it difficult to discuss their emotions or report distress[14,19].

Past research has shown that limited life experiences and a lack of confidence mean TYAs often struggle to cope with the challenges of cancer[6]. Studies have underscored the importance of bringing TYAs into conversations about their care to empower them and ensure their voice is heard[2]. Taking greater responsibility for their own healthcare, reading age-appropriate information, and engaging with psychological support can increase understanding and treatment adherence[5,7].

In the UK, psychosocial screening is a mandatory part of TYA cancer care and is important for guiding interventions[16]. However, it is unclear what validated psychosocial screening tools are available in this age group and clinical population. The British Psychological Society recommends that psychosocial screening tools used in cancer should be validated with standardised norms[29] and that clinicians should be aware of the psychometric properties and clinical utility of screening tools. However, in TYA cancer there is a lack of research into appropriate tools and their properties[19,30]. Validating existing screening tools could be one solution but new tools developed specifically for this group may also be needed[19].

Review Aims

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

Method

This systematic review adhered to PRISMA guidelines[31] and was registered with PROSPERO (07/02/22; reg no. CRD42022297985)[32]. 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 criteria[33].

Data Sources

Searches were conducted on 6th April 2022 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) framework[34] the main concepts identified were cancer, teenagers and young adults, and psychosocial screening tools. The keywords and subject headings are listed in Table 1. Each main concept was searched together using AND. No publication date or language restrictions were set.

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. 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 if they met the following criteria:

- Age group defined as adolescent or teenage or young adult/people. 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 tools used for screening purposes.

Studies were excluded if they met the following criteria:

- Paediatric or adult cancer (as above, no specific age range was set).
- Diagnosis other than cancer.
- Publications not written in English.
- Studies using psychosocial screening tools in TYA cancer survivors (i.e. beyond the diagnosis and treatment stage).

COSMIN guidelines include the following eligibility criteria for systematic reviews of screening tools[33]:

- Tools should measure the construct of interest, in this case psychosocial difficulties.
- The study sample should represent the population of interest, in this case TYA cancer.
- The study should concern screening tools.
- The study's aim should be to evaluate psychometric properties or to develop a tool.

However, as our primary aim was to identify which psychosocial screening tools are used in TYA cancer, we purposefully included studies only using screening tools 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.

The data extraction table includes:

1. Setting (participant recruitment, data collection, and location).
2. Whether the measure was used during routine clinical care or as part of a research study.
3. Sample size.
4. Age range of participants.
5. Cancer diagnoses of participants.
6. Language of the measure (where not stated this was assumed based on the setting).
7. Purpose of the measure (screening tool, outcome, predictor, covariate, or validation tool[*]).
8. Psychosocial construct being measured.
9. Mode of administration ('self-report' was stated if the paper reported self-report but made no reference to paper or online).
10. Number of items and subscales.
11. Response format (e.g. participants responded from 0 (not at all) to 3 (nearly every day)).
12. How the measure was scored and any cut-off points.

The tools identified in this review were not always used as screening tools (e.g., some were used to assess outcomes). Therefore, for the remainder of this review, we will refer to all

[*] Predictors were tools that were used as independent variables in a regression analysis. Outcomes were tools that were used to assess the impact of changing independent variables. Covariates were tools that measured a variable that affected an outcome but was not the variable of interest. Screening tools were used to identify people with a construct of interest. Validation tools were used as a comparison for other tools.

tools as 'measures'. Some studies 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 review[33]. 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 screening tools 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 properties[33] as sufficient (+), insufficient (-), or indeterminate (?). COSMIN recommends pooling findings together to identify the most suitable screening tool. However, this was not possible due to the small number of measures identified and the wide range of constructs covered.

Psychometric properties for tools 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 involves summarising the findings from the different studies based mainly on the use of words and text.

Quality Assessment

All papers retained after screening were assessed by KH using either the COSMIN risk of bias checklist[35] 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 checklist[35]

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 included the following sections:

- Screening tool development
- Content validity
- Structural validity
- Internal consistency
- Cross-cultural validity/measurement invariance
- Reliability
- Measurement error
- Construct validity, split into convergent validity and discriminative or known groups validity
- Responsiveness, split into comparison with other instruments, between subgroups, and before and after intervention.

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"[33]. Since the aim of this review was to identify the psychosocial screening tools used 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 tools[36] 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).

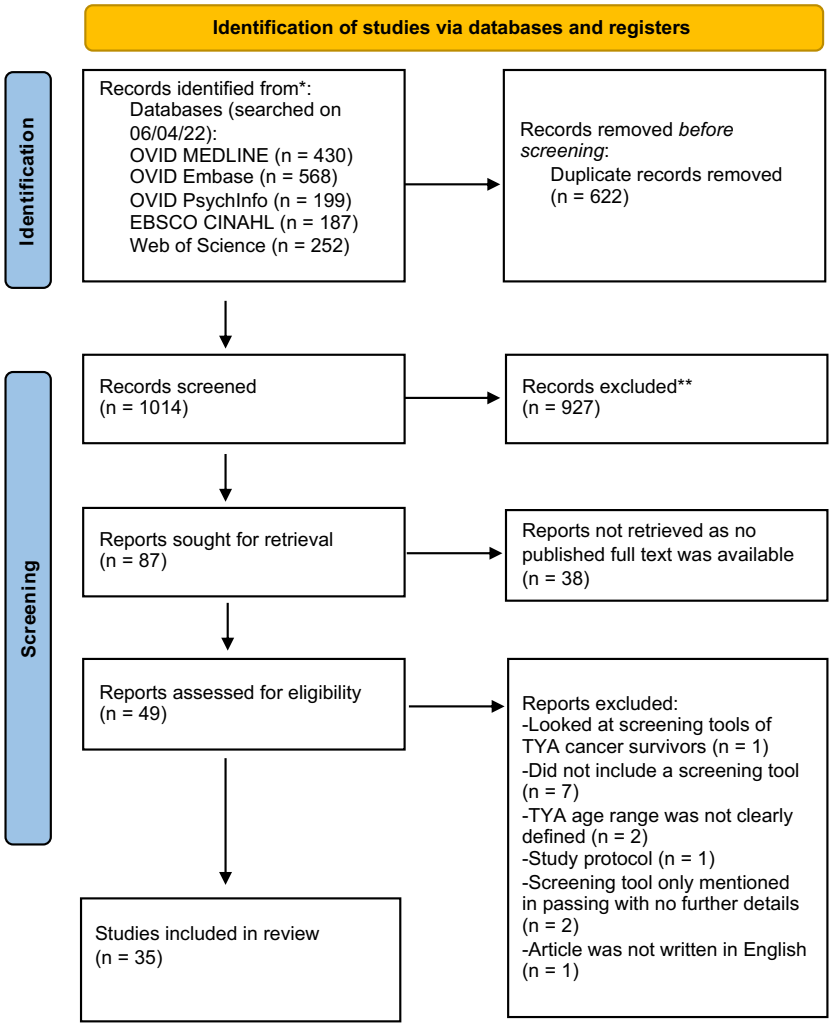
Results

Aim 1: Identify the psychosocial screening tools available for TYAs with cancer

Overview of studies

From five databases we identified 1014 papers after the removal of duplicates (Figure 1). 927 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 87 papers, full texts were retrieved for 49 papers. We were unable to retrieve full texts for 38/87 papers, despite contacting all corresponding authors who had shared their email to request full texts. Of the 49 papers retrieved, 14/49 were excluded as they did not meet the eligibility criteria for this review. Excluded papers were those addressing measures for TYA cancer survivors (n=1); not mentioning a measure (n=7); not defining a TYA age range (n=2); not providing any details about the measure (n=2); study protocol (n=1); and not written in English (n=1). 35 studies were therefore included in this review.

Figure 1. PRISMA flow chart of search results



Study and measure characteristics

The 35 studies were carried out in 12 countries. These countries were predominantly the USA (n=9 studies), Canada (n=7), China (n=3), Germany (n=3), Australia (n=3), UK (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). 28/35 studies were carried out in a research setting and 7/35 in a clinical setting. TYA ages ranged from 11-45 and the most commonly-reported age ranges were 18-39 (n=11) and 15-39 (n=11). The UK definition of TYAs aged 16-24 was used in only one study. Most studies covered a wide range of cancer diagnoses but two focused on breast cancer only and one on germ cell tumours only.

We identified 97 measures across the 35 studies since some studies included multiple measures (see Table 2). We identified measures in eight languages; predominantly English (n=22 studies), Chinese (n=3) and German (n=3). 46/97 (47%) measures were screening tools, 25/97 (26%) were outcomes, 15/97 (15%) were validation tools, 8/97 (8%) were predictors, 2/97 (2%) were outcomes and predictors, and 1/97 (1%) was a covariate. 36/97 (37%) measures were self-report with no mode of administration mentioned, 21/97 (22%) were paper self-report, 18/97 (19%) were paper or electronic self-report, 15/97 (15%) were electronic self-report, 3/97 (3%) were face-to-face interviews, 2/97 (2%) were not stated and 2/97 (2%) were not applicable as the paper focused on a discussion around the development of the measure.

The main constructs measured were distress (28/97 measures, 29%), depression (18/97, 18%), anxiety (15/97, 15%), quality of life (8/97, 8%), social support (6/97, 6%), psychosocial health/functioning (5/97, 5%), symptom burden (3/97, 3%) and medical coping (3/97, 3%). Despite distress being the most commonly-measured construct, it was clearly defined in only two papers[37,38] 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 (9/97 measures, 9%); Hospital Anxiety and Depression Scale (9/97, 9%); Distress Thermometer only (5/97, 5%); Patient Health Questionnaire in various forms e.g. PHQ-9, PHQ-8, PHQ-2 (5/97, 5%); Kessler Psychological Distress Scale- 10 and 6 (4/97, 6%); Generalised Anxiety Disorder Scale-7 (3/97, 3%); Canadian Problem Checklist (3/97, 3%); Paediatric Quality of Life Inventory (3/97, 3%); Cancer Distress Scales for Adolescents and Young Adults (3/97, 3%); and the PsychoSocial Screen for CANcer-Revised (3/97, 3%).

Quality Assessments

69/97 measures were assessed using the 'Hughes Quality Assessment Tool' (see Supplement A, Table 4) and 13/97 were assessed using the COSMIN Risk of Bias Checklist[35] (see Supplement A, Table 5). The remaining 15/97 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 67/69 (97%) measures and partially defined in 2/69 (3%). The population that the measure was validated in was adequately described in 25/69 (36%) measures, partially described in 20/69 (29%) and not described in 24/69 (35%). The measure was validated in a TYA cancer population for 10/69 (14%) measures.

Reliability

Reliability was reported for 28/69 (41%) measures. Internal consistency was reported for 18/69 (26%) measures with 14/69 (20%) reporting a statistic. Test-retest reliability was reported for 2/69 (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 38/69 (55%) measures. 3/69 (4%) reported on construct validity specifically but gave no statistic and 2/69 (3%) reported on convergent validity but again gave no statistic.

Interpretability

Very clear explanations of how to interpret scores was given for 33/69 (48%) measures, 26/69 (38%) were partially clear, 6/69 (9%) were not clear and 4/69 (6%) were not stated. Cut-offs were reported for 30/69 (43%) measures.

Method of administration

The method of administration was reported for 56/69 (81%) measures which was predominantly self-report (34 measures), paper self-report (15) and online self-report (9).

Cultural and language adaptations

18/69 (26%) measures were translated into another language and the psychometric properties were evaluated for 7 of these measures.

COSMIN Risk of Bias Checklist

13/97 measures were rated using this checklist.

PROM development

The development of 6/13 (46%) measures were reported with all methodologies rated as inadequate or doubtful.

Content validity

Patients were asked about the relevance, comprehensiveness, and comprehensibility for 4/13 (31%) measures with the majority of methodologies being rated as doubtful except McGrady et al. 2022[39] which had comprehensiveness and comprehensibility rated as adequate. Professionals were asked about relevance for 7/13 (53%) measures and comprehensiveness for 2/13 (15%). All were rated as doubtful.

Structural validity

Structural validity was reported for 3/13 (23%) measures; 2 were rated as very good and 1 as inadequate.

Internal consistency

Internal consistency was reported for 6/13 (46%) measures and all were rated as very good.

Cross-cultural validity

Cross-cultural validity was reported for 5/13 (38%) measures with 4 rated as inadequate and 1 as doubtful.

Reliability

Reliability was reported for 8/13 (62%) 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 10/13 (77%) measures; 5 were rated as adequate, 4 as doubtful and 1 as inadequate. Discriminative or known group validity was reported for 7/13 (54%) measures with 2 rated as very good and 5 as doubtful.

Responsiveness

10/13 (77%) measures were compared with other instruments. 5 were rated as adequate, 4 as doubtful and 1 as inadequate. 7/13 (54%) measures were compared between subgroups; 2 were rated as very good and 5 as doubtful. 5/13 (38%) measures were compared before and after an intervention and all were rated as doubtful.

Aim 2: Describe the psychometric properties of these tools

Of the identified measures, 13/97 were rated using COSMIN guidelines to describe their psychometric properties. 28/97 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 13 were validated in TYA cancer populations.

Measures rated using COSMIN guidelines (13/97)

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 4/13 (31%) measures. All measures were rated as 'insufficient' as they did not report adequate goodness-of-fit statistics.

Internal consistency

Internal consistency was reported for 6/13 (46%) measures, with 5 rated as sufficient (Cronbach alpha ≥ 0.70) and one as insufficient (Cronbach alpha < 0.70).

Cross-cultural validity/measurement invariance

Cross-cultural validity/measurement invariance was reported for 5/13 (38%) 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 9/13 (69%) 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 (28/97)

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%) measure and sensitivity/specificity was reported for 1/8 (13%) measure.

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 13 measures that were validated in TYA cancer populations:

Internal consistency (Cronbach alpha) was reported for 9/13 (69%) measures and ranged from 0.56-0.96 while sensitivity/specificity was reported for 5/13 (38%) measures.

Discussion

This systematic review found 97 psychosocial measures used in TYA cancer populations in 35 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 18-39 and 15-39. 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 and/or validated in a TYA cancer population. Reporting of psychometric properties was poor and most studies were generally of poor quality.

Previous research has shown that TYAs with cancer are at increased risk of distress, depression, and anxiety which can impact on pain, length of hospital admission and treatment adherence[40,41]. 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[37,38] meaning the construct being measured was unclear and there were possible overlaps with depression and

anxiety[41]. The Distress Thermometer is frequently used in adult cancer although there have been criticisms that this single-item tool could over-estimate levels of distress[42]. 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 treatments[2], it would be beneficial to explore whether measures' psychometric properties are stable across multiple diagnoses and treatments. Future research should focus on validating screening tools 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[43,44]; 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[19,43].

The reporting of psychometric properties was almost universally poor. Very few tools 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[19,42]. 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 adherence[45]. Although our review was restricted to publications written in English, and therefore found most measures were written in English, it is vital for screening tools to be translated and validated in a range of languages to ensure they are inclusive for all.

Strengths and limitations

This was the first study to comprehensively review the psychosocial measures 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, a large number of full texts were unavailable and therefore could not be included in this review. It is crucial for research to be accessible to allow clinicians and researchers to benefit from the findings. Finally, the gold standard for assessing the methodology and reporting psychometric properties of measures would be to follow COSMIN guidelines[33]. However, given that the main aim of this review was to identify the psychosocial screening tools available in 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 and a large proportion of the tools included were not validated in TYA cancer populations.

Conclusion

The use of psychosocial screening tools throughout cancer diagnosis and treatment can lead to early detection of mental health difficulties which allows for proactive rather than reactive interventions[42,46]. 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[20,44]. This systematic review identified a number of psychosocial screening tools 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 tools were not validated in a TYA cancer population and reporting of psychometric

properties was poor. This review highlights a crucial need for tools 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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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 screening tools	"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. Overview of Studies and Measures

		Clinical N studies (N measures)				**Research** 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)	1(2)			3(5)
	Canada	3(7)				1(2)	3(10)			
	China						3(12)			
	Germany					2(5)	1(2)			
	Australia							2(10)	1(2)	
	UK									2(10)
	Singapore						2(6)			
	Other						1(1)			5(12)

Supplement A

'Hughes Quality Assessment Tool'

The 'Hughes Quality Assessment Tool' assessed the following details:

- Conceptual and measurement model- this identified whether the concept was clearly defined, whether the population was adequately described and if so, was this population TYA cancer.
- Reliability and validity- this identified whether reliability and validity were reported and whether any statistics were given.
- Interpretability- this identified whether a clear explanation was given on how to interpret scores and whether cutoff points were reported.
- Method of administration.
- Cultural and language adaptations- this identified whether the tool was translated into another language and if so, if there was an evaluation of the tool's properties in that language.

Table 1. Psychometric Property Definitions (Adapted from COSMIN guidelines[1], Mokkink et al. 2010[2] and Lohr et al. 2002[3])

Psychometric Properties	Definition
Structural Validity	The degree to which scores on a tool are an adequate reflection of the dimensionality of the construct being measured
Internal Consistency	The degree of inter-relatedness among the items of a tool
Cross-Cultural Validity/Measurement Invariance	The degree to which the scores of the items on a translated/culturally adapted tool are an adequate reflection of the performance of the items on the original version of the tool
Reliability	The extent to which scores for individuals who have not changed are the same for repeated measurement under several conditions
Criterion Validity	The degree to which the scores of a tool are an adequate reflection of a gold standard
Test-Retest Reliability	The stability of a tool when it is measured over a period of time
Construct Validity	The extent to which a tool measures the construct it is supposed to
Sensitivity	The extent to which a tool can indicate an individual with the condition the tool is measuring
Specificity	The extent to which a tool can rule out people who do not have the condition that the tool is measuring
Content Validity	The degree to which the items of a tool are an adequate reflection of the construct that is being measured
Measurement Error	The systematic and random error of an individual's score that is not attributed to true changes in the construct being measured
Convergent Validity	Whether a tool designed to measure a particular construct correlates with other tools that assess the same/similar construct
Discriminative/Known Groups Validity	Whether constructs that theoretically should not be related are, in fact, unrelated

Table 2. Criterion Validity for COSMIN Papers

PROM	Country (language) in which the PROM was evaluated	Criterion validity	
		n	Result (rating)
Worry Thermometer (Cuffe et al. 2021)[4]	UK (English)	549	AUC = 0.753 Parent AUC = 0.712 (+) Sensitivity and specificity against 4 measures: Sensitivity: 13-17 years- 92.3 95% CI (64.0–99.8), 18+ years- 94.1 95% CI (80.3–99.3) Specificity: 13-17 years- 39.8 95% CI (29.5–50.8), 18+ years- 47.1 95% CI (34.8–59.6)
Learning Thermometer (Cuffe et al. 2021)[4]	UK (English)	549	AUC = 0.841 Parent AUC = 0.914 (+) Sensitivity and specificity against 4 measures: Sensitivity: 13-17 years- 92.9 95% CI (66.1–99.8), 18+ years- 93.3 95% CI (68.1–99.8) Specificity: 13-17 years- 66.0 95% CI (55.5–75.4), 18+ years 59.8 95% CI (48.7–70.1)
Adolescent & Young Adult Psychosocial Oncology Screening Tool (Consisting of the DT and AYA-NA) (Patterson et al. 2021)[5]	Australia, Canada, UK and USA (English)	288	HADS total: AUC = 0.84 HADS-Anxiety: AUC = 0.81 HADS-Depression: AUC = 0.81 (+) Sensitivity and specificity against HADS Sensitivity: Total- 0.82 HADS-A - 0.71 HADS-D - 0.84 Specificity: Total- 0.75

PROM	Country (language) in which the PROM was evaluated	Criterion validity	
		n	Result (rating)
			HADS-A - 0.81 HADS-D - 0.68 Pearson correlation between DT score and HADS: HADS-Total r = 0.65, p < 0.001 HADS-Anxiety r = 0.65, p < 0.001 HADS-Depression r = 0.48, p < 0.001
Cancer Distress Scales (CDS-AYA) (Rae et al. 2019)[6]	Canada (English)	453	AUC = 0.75- 0.85 for HADS anxiety AUC = 0.74–0.81 for HADS depression (+) Sensitivity and specificity against HADS: Sensitivity: Depression: Impact of cancer scale value 24: 70.2% Physical scale valye 27: 72.7% Emotional scale value 27: 78.3% Cognitive scale value 11: 78.9% Cancer worry scale value 36: 68.3% Anxiety: Impact of cancer scale value 34: 71.8% Physical scale value 32: 69.0% Emotional scale value 30: 80.3% Cognitive scale value 22: 73.2% Cancer worry scale value 41: 62.0% Specificity: Depression: Impact of cancer scale value 24: 71.3% Physical scale valye 27: 63.3% Emotional scale value 27: 78.9% Cognitive scale value 11: 64.7% Cancer worry scale value 36: 77.9% Anxiety: Impact of cancer scale value 34: 78.9% Physical scale valye 32: 73.9% Emotional scale value 30: 69.7% Cognitive scale value 22: 68.3%

PROM	Country (language) in which the PROM was evaluated	Criterion validity	
		n	Result (rating)
			Cancer worry scale value 41: 76.3%
Field test version of the Cancer Distress Scales for AYA (CDS-AYA) (Tsangaris et al. 2019)[7]	Canada (English)	409-515	Correlations between scores on the five CDS-AYA scales and scores on the HADS and ESAS-r (scale, r, n): Worry: ESAS 0.522 502 HADS anxiety 0.569 512 HADS depression 0.447 515 HADS total score 0.579 512 Impact ESAS 0.57 455 HADS anxiety 0.538 455 HADS depression 0.552 455 HADS total score 0.609 455 Cognition ESAS 0.547 499 HADS anxiety 0.557 509 HADS depression 0.517 509 HADS total score 0.599 509 Emotion ESAS 0.674 499 HADS anxiety 0.692 509 HADS depression 0.548 509 HADS total score 0.712 509 Physical ESAS 0.697 502 HADS anxiety 0.516 512 HADS depression 0.539 512 HADS total score 0.584 512 All p<.001 (-)
The Fatigue Scale–Adolescent instrument for 13- to 18-year old children- (Revised 13-item FS-A) (Mandrell et al. 2011)[8]	USA (English)	75	AUC = 0.797 (standard error, .091; 95% confidence interval, .617-.977) (+) Sensitivity and specificity against Fatigue Scale-Parents (FS-P): Sensitivity- 66.6% Specificity- 82.6% Concurrent validity FS-A and FS-P: Spearman correlation coefficient = 0.347 (P = 0.0033)

PROM	Country (language) in which the PROM was evaluated	Criterion validity	
		n	Result (rating)
Young Adult—Psychosocial Assessment (McGrady et al. 2022)[9]	USA (English)	100	Correlations with validated measures: Distress: Anxiety= 0.70***, Depression= 0.64***, Cognitive functioning= -0.46***, Post-traumatic stress= 0.39***, Family stressors= 0.31**, Support= -0.38***, Social isolation= 0.53***, Symptom management= -0.48***, Medication management= -0.08 Global mental health: Anxiety= -0.71***, Depression= -0.67***, Cognitive functioning= 0.49***, Post-traumatic stress= -0.51***, Family stressors= -0.23*, Support= 0.41***, Social isolation= -0.65*** General health: Symptom management= 0.57***, Medication management= -0.21 Emotional well-being: Anxiety= -0.73***, Depression= -0.71***, Cognitive functioning= 0.50***, Post-traumatic stress= -0.50***, Family stressors= -0.20 Social well-being: Support= 0.44***, Social isolation= -0.65*** Social support: Support= 0.70*** Counselling: Anxiety= 0.44***, Depression= 0.35***, Cognitive functioning= -0.41***, Post-traumatic stress= 0.29** Family counselling need: Family stressors= 0.21* Support group need: Support= -0.22*, Social isolation= 0.33**

PROM	Country (language) in which the PROM was evaluated	Criterion validity	
		n	Result (rating)
			*p < .05; **p < .01; ***p < .001 (-)

Table 3. Data Extraction Table

Reference Setting (Inc. country)	Clinical v Researcl	Sample Size	Age Range	Cancer Diagnoses	Language	Screening Tool (Purpose of Measure)	Construct Being Measured	Mode of Administration	No. of Items	Subscales	Response Format	Scoring	Cutoff
Glidden et al. 2022[10] Participants recruited to an online survey through social media sites of Young Adult Cancer Canada (YACC), various Canadian AYA cancer support groups, and paediatric and adult oncology clinics at CancerCare Manitoba	Research	805	18-39	Haematological Non-haematological	English and French	Kessler Psychological Distress Scale (K10) (Outcome)	Psychological distress	Online self-report	10	Not stated	Items rated on a 5-point Likert scale	Scores were summed and total scores ranged from 10 to 50	<20 no significant distress, 20-24 mild distress, 25-29 moderate distress, 30-50 severe distress
						Research survey titled "Impact of COVID-19 Pandemic on Adolescents and Young Adults with Cancer in Canada" (Outcome)	COVID-19 related worries, psychosocial support, and sociodemographic and clinical information	Online self-report	49	Not stated	COVID-19 related worries were rated using a 5-point Likert scale from 1 (not at all worried) to 5 (very worried). TYAs reported type and use of psychosocial support and rated how satisfied they were with this support from 1 (not satisfied at all) to 5 (very satisfied). Demographic and health information was collected	Not stated	Not stated
Cuffe et al. 2022[4] Participants were recruited from seven Children's Cancer and	Research	549 (<12 years n=334, 13-17 years n=113, 18+ years n=102)	0-22 but only measures used for 13-22 included here	Bone Brain Leukaemia Neuroblastoma Sarcoma Other	English	Worry Thermometer/Learning Thermometer and Coping list (Screening tool)	Distress and learning problems	Paper self-report	2 thermometers and 6 item checklist	Checklist categorised into: How you feel, Practical issues, Memory/learning, My lifestyle, Problems with my body,	Visual analogue scale ranging from 0 to 10 with 10 indicating significant difficulties	Higher scores = greater distress/higher likelihood of learning problems	None

Reference Setting (Inc. country)	Clinical v Researcl	Sample Size	Age Range	Cancer Diagnoses	Language	Screening Tool (Purpose of Measure)	Construct Being Measured	Mode of Administration	No. of Items	Subscales	Response Format	Scoring	Cutoff
Leukaemia groups (UK)										Would you like help with these problems?			
						Strengths and Difficulties Questionnaire (Validation tool)	Psychological functioning	Paper self-report (parent and child form)	25	Not stated	Not stated	Not stated	Scores of ≥20 on the child version and ≥17 on the parent version indicate emotional distress
						Hospital Anxiety and Depression Scale (Validation tool)	Anxiety and depression	Paper self-report	14	Anxiety Depression	Not stated	Total and subscale scores calculated	≥15 indicates emotional distress
						Health Utilities Index Mark 2 (HUI1)- Cognition Domain (Validation tool)	Memory/learning difficulties and problem solving abilities	Paper self-report	2	Memory/learning difficulties Problem solving abilities	Not stated	Not stated	≥3 indicates difficulties
						Pediatric Quality of Life Inventory (PedsQL) (only suitable for ages 2-18) (Validation tool)	Quality of Life	Paper self-report (parent and child form)	23	Physical Emotional Social School	Not stated	Total and subscale scores were summed and two summary scores were calculated (psychosocial and physical)	Total score for children ≥8: ≥78 normal, 71-77 moderate problems, ≤70 major chronic condition
						Medical Outcomes Survey Short Form-8 (SF-8) (Validation tool)	Quality of Life	Paper self-report	Not stated	Not stated	Not stated	Not stated	Problem cases are those whose total score is within the worst quartile
Kivlighan et al. 2022[11] Large cancer centre in a teaching hospital (Midwestern US). All patients complete	Clinical	1700	18-39	Haematology Pulmonary Gynaecological Surgical Urology	English	Distress Screening Questionnaire (Covariate)	Distress	Self-report	4	Practical problems, Family problems, Emotional problems	Distress thermometer- 1 item visual analogue scale from 1 (low distress) to 10 (high distress). Three yes/no questions assessing each subscale	Higher scores = greater distress	Not stated

Reference Setting (Inc. country)	Clinical v Researcl	Sample Size	Age Range	Cancer Diagnoses	Language	Screening Tool (Purpose of Measure)	Construct Being Measured	Mode of Administration	No. of Items	Subscales	Response Format	Scoring	Cutoff
the measure prior to their first appointment and every 3 months after that													
Duan et al. 2021[12] Participants were inpatients recruited from 4 hospitals in Hunan, China between March and October 2021	Research	1000	15-39	Digestive system malignancies, Haematological malignancies, Gynaecological malignancies, Lung cancers, Breast cancers, Head and neck malignancies, Skin cancers, Other	Chinese	Distress Thermometer (Chinese Version) (Outcome)	Distress	Paper self-report	1 distress thermometer plus a problem list	Emotional distress, Family distress, Physical distress, Practical distress, Spiritual distress	Distress thermometer- 1 item visual analogue scale from 1 (no distress) to 10 (extreme distress). No information on the response format of the problem list	Higher scores = greater distress	≥4 indicated distress
						Three-Dimensional Inventory of Character Strengths (Predictor)	Character strengths	Paper self-report	15	Caring Inquisitiveness Self-control	Each rated was rated from 1 (very much unlike me) to 5 (very much like me)	Each subscale score was calculated by summing the score of each item	Not stated
						Medical Coping Modes Questionnaire (Predictor)	Medical coping	Paper self-report	10	Confrontation (8 items), Avoidance (7 items), Acceptance (5 items)	Responses for 12 items ranged from 1 (never) to 4 (often), and for 8 items responses were inverted from 1 (often) to 4 (never)	Total scores for each subscale were calculated. Higher scores = increased use of each coping strategy	Not stated
						Social Support Rating Scale (Predictor)	Social support	Paper self-report	10	Objective support (3 items), Subjective support (4 items), Support utilization (3 items)	Most items (excluding questions about sources of support) were rated from 1 (never seek help from others) to 4 (actively seek help from others)	Total scores ranged from 11 to 62. Higher scores = better social support	Not stated

Reference Setting (Inc. country)	Clinical v Researcl	Sample Size	Age Range	Cancer Diagnoses	Language	Screening Tool (Purpose of Measure)	Construct Being Measured	Mode of Administration	No. of Items	Subscales	Response Format	Scoring	Cutoff
Patterson et al. 2021[5] TYAs were recruited from 28 cancer centres in Australia, Canada, UK and USA. Participants were recruited within 3 months of diagnosis and completed the survey in hospital or at home	Research	288	15-29	Lymphoma Leukaemia Germ cell cancer Sarcoma Carcinoma Brain and CNS Other Unsure	English	Adolescent and Young Adult Psychosocial Screening Tool (Screening tool)	Distress	Paper or online self-report	1 distress thermometer plus 40 item problem list	Practical Family Emotional Physical Social Information	Participants rated their distress over the last week from 0 (no distress) to 10 (high distress) and responded yes/no to the problem list	Higher scores = greater distress. Frequency of yes responses were recorded for the problem list	≥5 indicates distress
						Hospital Anxiety and Depression Scale (Validation tool)	Anxiety and depression	Paper or online self-report	14	Anxiety Depression	Not stated	Not stated	≥15 indicates clinical levels of distress in distress thermometer validation studies. In 12-17 year olds cutoffs of ≥9 and ≥7 indicate clinical levels of anxiety and depression respectively
Jacobson et al. 2022[13] Eight UK cancer services recruited participants for an online study. Participants were identified by local teams and were invited to take part via text or email from their team	Research	112	16-30	Haematological Neurological Skin Head and neck Endocrine Urology Gynaecological Breast Sarcoma Other	English	Patient Health Questionnaire (PHQ-8) (Outcome)	Depression	Online self-report	8	Not stated	Not stated	Each item's score ranges from 0-3 so a total severity score ranges from 0-24	10-14 moderate distress, 15-19 moderately-severe, 20-24 severe
						Generalised Anxiety Disorder Scale (GADS-7) (Outcome)	Anxiety	Online self-report	7	Not stated	Not stated	Each item's score ranges from 0-3 so a total severity score ranges from 0-21	5 mild, 10 moderate, 15 severe anxiety
						COVID-19 Questionnaire (no name given) (Outcome)	Impact of COVID-19	Online self-report	6	Not stated	Participants were asked to rate whether they had experienced more, less or no change in anxiety since COVID-19 began. 5	Not stated	Not stated

Reference Setting (Inc. country)	Clinical v Researcl	Sample Size	Age Range	Cancer Diagnoses	Language	Screening Tool (Purpose of Measure)	Construct Being Measured	Mode of Administration	No. of Items	Subscales	Response Format	Scoring	Cutoff
											statements were responded to on a 6 point Likert scale (strongly disagree, disagree, neither agree nor disagree, agree and strongly agree)		
						Connor-Davidson Resilience Scale (CD-RISC) (Predictor)	Resilience	Online self-report	2	Not stated	Not stated	Total scores range from 0-8. Higher scores = greater resilience	Not stated
Giberson et al. 2021[14] Outpatient cancer support service clinic in the US for patients receiving cancer support services e.g. social work consultation. Patients were screened as part of routine clinical care. Data was collected between October 2015 and September 2016 for a sequential	Clinical	500 (52 TYAs, 448 older adults)	TYAs 18-39 OAs 40-86	Breast, Digestive System, Female genital system, Lung, Male genital system, Lymphoma, Head and neck, Urinary system, Leukaemia, Endocrine, Sarcoma, Skin, Myeloma, Brain and other CNS	English	Patient Health Questionnaire (PHQ-2) (Screening tool)	Depression	Online self-report using tablets	2	Depressed mood Anhedonia	Patients respond on a 4-point Likert scale from 0 (not at all) to 3 (nearly every day)	Item scores are summed to give a total score	≥3 triggers the PHQ-9
						Patient Health Questionnaire (PHQ-9)- an abbreviated version of the PHQ-2 is used initially to screen for symptoms of depression and is the patient scores >3 then the PHQ-9 is automatically triggered (Screening tool)	Depression and suicidal ideation	Online self-report using tablets	9	Depressed mood Suicidal thoughts	Patients respond on a 4-point Likert scale from 0 (not at all) to 3 (nearly every day)	Item scores are summed to give a total score	≥5 indicates possible depression. ≥1 on the item on suicidal thoughts is consider a positive screen for suicidal ideation

Reference Setting (Inc. country)	Clinical v Researcl	Sample Size	Age Range	Cancer Diagnoses	Language	Screening Tool (Purpose of Measure)	Construct Being Measured	Mode of Administration	No. of Items	Subscales	Response Format	Scoring	Cutoff
sample of patients													
Tan et al. 2020[15] Secondary analysis from a longitudinal cohort study conducted as the National Cancer Centre in Singapore. Patients were recruited in outpatient oncology clinics if they were newly referred to an oncologist and met the eligibility criteria	Research	91 at baseline and 82 completed the data set for at least one follow-up time point	15-39	Sarcoma, Lymphoma, Germ cell tumour, Melanoma, Pancreatic neoplasm, Nasopharyngeal neoplasm	Not stated	Functional Assessment of Cancer Therapy-Cognitive Function (FACT-Cog) Version 3 (Outcome)	Cancer-related cognitive impairment	Self-report	37	Perceived cognitive impairment, Comments from others, Perceived cognitive abilities, Impact on quality of life	Not stated	Scores on negatively worded items were reversed and a total score was calculated from summing the scores from all subscales. Higher scores = better self-perceived cognitive function	<60 indicates cancer-related cognitive impairment cases
						Distress Thermometer and Problem Checklist (Outcome)	Distress	Self-report	1 item distress thermometer plus a 43 item problem checklist	Problem checklist includes memory and cognition	Participants rate the level of distress they have experienced in the past week on a scale from 0 to 10	Higher scores = greater distress	>5 indicates clinically significant distress
						Rotterdam Symptom Checklist (RSCL) (Outcome)	Symptom burden including anxiety/depression symptoms and fatigue	Self-report	39	Physical (23 items) Psychological (7 items) Activity levels (8 items) Overall valuation of life (1 item)	Participants rated the extent to which they were bother by specific symptoms in the past week on a 4-point Likert scale	Higher scores = greater symptom burden or impairment	>16 on the psychological subscale indicated anxiety/depression symptoms. >3 on the fatigue item indicated significant fatigue
Smrke et al. 2020[16] A cancer program within British Columbia, Canada. Retrospective review	Clinical	2045	18-39	Breast Cervix/endometrial Gastrointestinal Lymphoma Melanoma CNS Sarcoma Thyroid Other Testes Renal	English	Canadian Problem Checklist (CPC) (Screening tool)	Distress	Self-report	21	Emotional Informational Practical Spiritual Social Physical	Patients selected which of the common concerns of problems they had experienced in the past week	Concerns were grouped into subscales and percentages of yes answers were recorded	Not stated
						PsychoSocial Screen for Cancer- Revised	Anxiety and depression	Self-report	Not stated	Anxiety Depression	Levels of distress were assessed on a 5-	Mean scores were calculated	1-7= low anxiety of depression

Reference Setting (Inc. country)	Clinical v Researcl	Sample Size	Age Range	Cancer Diagnoses	Language	Screening Tool (Purpose of Measure)	Construct Being Measured	Mode of Administration	No. of Items	Subscales	Response Format	Scoring	Cutoff
of patients between 2011 and 2916 who completed the screening tools within 6 months of their cancer diagnosis				Ovarian Lung Salivary		(PSSCAN-R) (Screening tool)					point Likert scale from 0 (not at all) to 5 (very much)		8-10= moderate anxiety of depression ≥11 = severe anxiety of depression
						Support Network and Support Assessment Tool (Screening tool)	Social support	Self-report	Not stated	Not stated	Patients were asked dichotomous items e.g. whether they lived alone or had emotional support	Not stated	Not stated
Tsangaris et al. 2019[7] Field test of the Cancer Distress Scales for AYAs which recruited participants between August 2016 and November 2017 during their scheduled clinic appointments at a number of hospitals/cancer centres in Canada	Research	515 (test-retest group=86)	15-39	Carcinoma Leukaemia Lymphoma Sarcoma Other Not reported	English	Field test version of the Cancer Distress Scales for AYA (CDS-AYA) (Screening tool)	Distress	Paper or electronic self-report	91	Impact of cancer Physical Emotional Cognitive Cancer worry Cognitive Employment Education Practical Social	Distress experienced in the past week was rated using 4 response options-none, mild, moderate, severe	Scores were transformed onto a scale from 0 (no distress) to 100 (most distress)	Not stated
						NCCN Distress Thermometer (Validation tool)	Distress	Paper or electronic self-report	1	None	Distress experienced in the past week was measured on a scale from 0 (no distress) to 10 (extreme distress)	Higher scores = greater distress	Not stated
						Hospital Anxiety and Depression Scale (HADS) (Validation tool)	Anxiety and depression	Paper or electronic self-report	14	Anxiety Depression	Answered on a 4-point scale from 0 to 3.	Higher scores = greater symptoms of anxiety/depression	Not stated
						Edmonton Symptom Assessment Scale revised (ESAS-r) (Validation tool)	Symptom distress	Paper or electronic self-report	9	Pain, Tiredness, Nausea, Depression, Anxiety, Drowsiness, Appetite, Feeling of well-being,	Participants reported their symptoms on a scale from 0 (none) to 10 (worst) on how they felt at time of completion	Higher scores = worse symptoms	Not stated

Reference Setting (Inc. country)	Clinical v Researcl	Sample Size	Age Range	Cancer Diagnoses	Language	Screening Tool (Purpose of Measure)	Construct Being Measured	Mode of Administration	No. of Items	Subscales	Response Format	Scoring	Cutoff
										Shortness of breath			
Rae et al. 2020[17] Used data from the field test of the Cancer Distress Scales for AYAs (Tsangaris et al. 2019)	Research	421	15-39	Carcinoma Leukaemia Lymphoma Sarcoma Other Not reported	English	Cancer Distress Scales for Adolescents and Young Adults (CDS-AYA) (Screening tool)	Distress	Paper or electronic self-report	49	Impact of cancer Physical Emotional Cognitive Cancer worry	Distress experienced in the past week was rated using 4 response options-none, mild, moderate, severe	Items were summed within each scale and transformed onto a scale of 0-100. Each scale was independent so no overall score was given. Higher scores = greater distress	Distress is defined by: ≥24 on the impact of cancer scale ≥27 on the emotional scale
						Edmonton Symptom Assessment Scale-Revised (Screening tool)	Distress	Paper of electronic self-report	9	Anxiety Depression (not clearly stated)	Participants responded on how they felt at the time of completion of a 11-point scale from 0 (none) to 10 (severe)	Not stated	≥4 on anxiety or depression symptom items requires action to address distress
						Distress Thermometer (NCCN-DT) (Screening tool)	Distress	Paper or electronic self-report	1	None	Participants rate the level of distress they have experienced in the past week on a scale from 0 (no distress) to 10 (highest levels of distress)	Higher score = greater distress	≥4 prompts clinicians to ask additional questions
						Hospital Anxiety and Depression Scale (Screening tool)	Anxiety and depression	Paper or electronic self-report	14	Anxiety Depression	Participants answered with 4 response options based on how they were feeling over the past week	Scores are summed for each scale with higher scores indicating greater symptoms of depression/anxiety. Total scores	<8 = normal 8-10 = borderline abnormal 11-21 = abnormal Cutoff for total score >16

Reference Setting (Inc. country)	Clinical v Researcl	Sample Size	Age Range	Cancer Diagnoses	Language	Screening Tool (Purpose of Measure)	Construct Being Measured	Mode of Administration	No. of Items	Subscales	Response Format	Scoring	Cutoff
												range from 0-21	
Naik et al. 2020[18] Standardised screening program at British Columbia Cancer Centre in Canada. Offered the screening tool to all ambulatory patients on their first visit after diagnosis and before treatment	Clinical	10734 overall, 420 young adults, 10314 older adults	Young adults = 18-39, Older adults = >39	Breast	English	Psychosocial Screen for Cancer-Revised (PSSCAN-R) (Screening tool)	Distress, anxiety and suicidal ideation	Paper self-report	10	Anxiety Depression	4-point Likert system from 0 (not at all) to 4 (very much so)	Higher scores = greater levels of anxiety/depression	8-10 = moderate/subclinical anxiety/depression ≥11 = severe/clinical anxiety/depression
						Canadian Problem Checklist (CPC) (Screening tool)	Common concerns experienced by patients	Paper self-report	21	Emotional Practical Social/family Informational Spiritual Physical	Patients were asked to check off whether they had experienced any of the problems over the past week	Not stated	Not stated
Rae et al. 2019[6] Used data from the field test of the Cancer Distress Scales for AYAs (Tsangaris et al. 2019)	Research	453	15-39	Carcinoma Leukaemia Lymphoma Sarcoma Other	English	Cancer Distress Scales (CDS-AYA) (Screening tool)	Distress	Paper or electronic self-report	48	Impact of cancer Physical Emotional Cognitive Cancer worry	For each item participants reported how much distress they had experienced in the past week using 4 options (none, mild, moderate, severe)	For each scale items were summed and transformed onto a scale of 0-100 with higher scores meaning greater distress	Emotional scale cutoffs: 27 anxiety 30 depression Impact of cancer scale cutoffs: 24 anxiety 34 depression Optimal screening cutoffs: 27 for emotional scale 24 for impact of cancer scale

Reference Setting (Inc. country)	Clinical v Researcl	Sample Size	Age Range	Cancer Diagnoses	Language	Screening Tool (Purpose of Measure)	Construct Being Measured	Mode of Administration	No. of Items	Subscales	Response Format	Scoring	Cutoff
						Hospital Anxiety and Depression Scale (HADS) (Validation tool)	Anxiety and depression	Paper or electronic self-report	14	Anxiety Depression	Participants reported how they felt for the past week using 4 response options	Subscale scores are generated and range from 0 to 21. Higher scores = greater symptoms of depression/anxiety	<8 = normal 8-10 = borderline abnormal 11-21 = abnormal
Geue et al. 2018[19] Participants were recruited from cancer institutions associated with regional study centres in Germany	Research	302	15-39	Breast cancer, Cancer of female genital organs, Colon/rectum cancer, Haematological neoplasm, Testicular cancer, Other	German	Patient Health Questionnaire (PHQ-9) (Screening tool)	Depression	Self-report	9	None	Participants responded on a Likert scale from 0 (not at all) to 3 (nearly every day) about depressive symptoms they experienced in the past 2 weeks	A total score was calculated from 0 to 27. Higher score = greater frequency of depressive symptoms	>9 indicates a cutoff for any depressive disorder
						Generalised Anxiety Disorder Scale (GAD-7) (Screening tool)	Anxiety	Self-report	7	None	Participants responded on a Likert scale from 0 (not at all) to 3 (nearly every day)	A total score was calculated from 0 to 21	0-4 = no anxiety 5-9 = mild 10-14 = moderate ≥15 = severe
Chan et al. 2018[20] Participants were referred by their oncologist during their first visit to the National Cancer Centre Singapore between September 2015 and	Research	65	15-39	Lymphoma Sarcoma Germ cell tumours Neuro-oncological Melanoma	English	Distress Thermometer (Screening tool)	Distress	Self-report	1 thermometer plus and problem checklist	Practical, Family, Emotional, Spiritual and religious, Physical problems	Thermometer contained a scale from 0 to 10 for participants to rate their level of distress	Greater score = greater distress	≥4 indicates clinically significant distress
						Rotterdam Symptom Checklist (Screening tool)	Symptom burden	Self-report	39	Psychological and physical symptom burdens, Patient's activity levels, Overall quality of life	Not stated	Raw scores were transformed into scores from 0 (lowest impairment) to 100 (highest impairment) that allowed comparisons across	Not stated

Reference Setting (Inc. country)	Clinical v Researcl	Sample Size	Age Range	Cancer Diagnoses	Language	Screening Tool (Purpose of Measure)	Construct Being Measured	Mode of Administration	No. of Items	Subscales	Response Format	Scoring	Cutoff
September 2017												different aspects of the checklist	
						PedsQL Generic Core Scales (Screening tool)	Physical and psychosocial health	Self-report	21	Only stated 'four scales'	Not stated	Responses were coded from 0 (greatest incidence) to 100 (least incidence). Greater scores = better health outcomes	Not stated
Xie et al. 2017[21] Participants were recruited from inpatients a number of hospitals in Hunan, China between November and December 2014	Research	610	15-39	Digestive system cancers Haematological Gynaecological Lung Breast Head and neck Skin Other malignancies	Chinese	Distress Thermometer (Outcome)	Distress	Self-report	1 thermometer plus a problem list	Sources of distress: Emotional Family Physical Practical Spiritual	Participants rated their level of distress from 0 (no distress) to 10 (extreme distress)	Higher scores = greater distress	Not stated
						Hospital Anxiety and Depression Scale (Outcome)	Anxiety and depression	Self-report	14	Not stated	Not stated	Items for each subscale are summed to create scores for depression/anxiety ranging between 0 and 21. Higher scores = higher levels of anxiety/depression	>9 indicates anxiety or depression
						Medical Coping Modes Questionnaire (Outcome)	Coping	Self-report	20	Confrontation Avoidance Acceptance	12 items are scored from 1 (never) to 4 (very often) and 8 items are reverse scored from 1 (very often) to 4 (never)	Higher scores = increased use of the coping strategy	Not stated
						Social Support Rating Scale (Outcome)	Social support	Self-report	10	Objective support,	4-point Likert scale ranging from 1 (never	Higher scores = more social support	Not stated

Reference Setting (Inc. country)	Clinical v Researcl	Sample Size	Age Range	Cancer Diagnoses	Language	Screening Tool (Purpose of Measure)	Construct Being Measured	Mode of Administration	No. of Items	Subscales	Response Format	Scoring	Cutoff
										Subjective support, Support utilization	seeking help from others) to 4 (actively seeking help from others. Other questions ask for the number of sources of support		
Sun et al. 2019[22] Participants were recruited by a consecutive sampling method from two hospitals in Guangdong, China where they were asked to participate through an outpatient consultation	Research	249	15-39	Breast Leukaemia Colorectal Nasopharynx	Mandarin or Cantonese	Information Sheet (Outcome)	Demographic, clinical and psychological information	Self-report	14	Demographic- 4 items on age, gender etc. Clinical- 7 items on cancer type, stage etc. Psychological- 3 items on personality tendency, stressful life events etc.	Yes/no questions, multiple choice questions and the personality tendency question was measured with a single question from the Personality Traits Questionnaire (What do you think is your dominant personality trait?)	Not stated	Not stated
						Fear of Progression Questionnaire-Short Form (FoP-Q-SF) (Outcome)	Fear of cancer recurrence	Self-report	12	Not stated	Participants responded on a scale from 1 (never) to 5 (very often)	Total scores ranged from 12 to 60. Higher scores = higher fear of cancer recurrence	≥34 indicates a dysfunctional level of fear of cancer recurrence
						Generalised Anxiety Disorder Questionnaire (GAD-7) (Outcome)	Anxiety	Self-report	7	None	Participants response options are 0 (not at all), 1 (several days), 2 (more than half the days) or 3 (nearly every day)	Higher scores = higher anxiety	≥5 indicates anxiety symptoms
						Patient Health Questionnaire (PHQ-9) (Outcome)	Depression	Self-report	9	None	Participants responded from 0 (not at all) to 3 (nearly every day)	Higher scores = higher depression	≥5 indicates depressive symptoms

Reference Setting (Inc. country)	Clinical v Researcl	Sample Size	Age Range	Cancer Diagnoses	Language	Screening Tool (Purpose of Measure)	Construct Being Measured	Mode of Administration	No. of Items	Subscales	Response Format	Scoring	Cutoff
Chalmers et al. 2018[23] Participants were recruited from 5 hospitals in New South Wales, Australia at their bedside or before or after a clinic appointment	Research	19	15-25	Acute lymphoblastic leukaemia, Acute myeloid leukaemia, Brain cancer, Hodgkin's Lymphoma, Non-Hodgkin's Lymphoma, Sarcoma of the bone, Soft tissue sarcoma, Other	English	AYA Oncology Psychosocial Assessment Measure (modified version of the HEADSS) (Screening tool)	Psychosocial measure assessing home environment, education/employment, social history, drug/alcohol use, sexuality and mental health	Face-to-face or telehealth semi structured clinical interview	Not stated	Home environment, Education or employment status, Social history, Drug or alcohol use, Sexuality, Mental health status	Not stated	Not stated	Not stated
						Youth Satisfaction Questionnaire (Outcome)	Satisfaction with overall psychosocial care	Paper or electronic self-report	Not stated	Not stated	Not stated	Scores range from 3 to 9. Higher scores = higher patient satisfaction	Not stated
						Kessler Psychological Distress Scale 10 (Outcome)	Anxiety and depression	Paper or electronic self-report	10	Not stated	Not stated	Scores range from 10 to 50	<20 = normal functioning 20-24 = mild difficulties 25-29 = moderate difficulties >30 = severe difficulties
						Pediatric Quality of Life Inventory for Adolescents and Young Adults (Outcome)	AYA cancer-specific quality of life	Paper or electronic self-report	Not stated	Physical health, Emotional, Social, Study/work, Pain and hurt, Nausea, Procedural anxiety, Treatment anxiety, Worry, Cognitive problems, Physical appearance, Communication	Not stated	Scores range from 0 to 100. Higher scores = higher quality of life	Not stated

Reference Setting (Inc. country)	Clinical v Researcl	Sample Size	Age Range	Cancer Diagnoses	Language	Screening Tool (Purpose of Measure)	Construct Being Measured	Mode of Administration	No. of Items	Subscales	Response Format	Scoring	Cutoff
McCarthy et al. 2016[24] Participant were identified by local staff from 17 hospitals in Australia using clinical databases	Research	196 AYAs 204 parents	15-25	Malignant haematological, Hodgkin lymphoma, Sarcoma, Brain, Germ cell, Melanoma, Thyroid, Other	English	Posttraumatic Stress Disorder Checklist (PCL-S) (Outcome)	PTSD	Paper self-report	17	Not stated	AYAs and parents rated on a 5-point scale the extent to which they have been bothered by symptoms over the past month	Total scores ranged from 0 to 85	≥3 for any item considered a symptom was an indication of PTSD. Other studies report scores of 30 and 40 as cut-offs to indicate participants at risk of PTSD
						Kessler Psychological Distress Scale (K10) (Outcome)	Distress	Paper self-report	10	Anxiety Depression	Participants responded on a 5-point scale	Total scores ranged from 10 to 50	Not stated
						Multidimensional Scale of Perceived Social Support (MSPSS) (Predictor)	Social support	Paper self-report	12	Support from family, Support from friends, Support from significant others	Not stated	Not stated	Not stated
						Medical Outcomes Social Support Survey (MOS) (Predictor)	Social support	Paper self-report	Not stated	Social support was measured across four domains	Not stated	Not stated	Not stated
						Life Impact Scale (modified to assess cancer impacts relevant to AYAs) (Predictor)	Positive and negative impacts of cancer	Paper self-report	18 items for AYAs 13 items for parents	Not stated	Participants responded on a 6-point scale. 2 additional items were added for parents to capture the impact of their child's cancer on themselves and the family	Not stated	Not stated
						"Are there other life stresses that you feel have affected how you have been able to cope with your (or your	Life stress	Paper self-report	1	None	Qualitative answers were given	Not stated	Not stated

Reference Setting (Inc. country)	Clinical v Researcl	Sample Size	Age Range	Cancer Diagnoses	Language	Screening Tool (Purpose of Measure)	Construct Being Measured	Mode of Administration	No. of Items	Subscales	Response Format	Scoring	Cutoff
						son or daughter's) cancer diagnosis or treatment?" (Predictor)							
Burgoyne et al. 2015[25] Retrospective cross-sectional chart review of participants who completed the screening tool during their first or second outpatient appointment between May 2008 and May 2011 from a local and regional cancer centre in Midwestern US	Clinical	668 young adults, 3238 middle aged adults, 2019 seniors	Young adults= 18-39, Middle aged= 40-64, Senior= 65-90	Prostate/urologic Blood/lymphatic Head and neck Breast Neurologic Hepatobiliary Gynaecologic Thoracic Colorectal Skin Endocrine Bone/connective tissue	English	Distress Thermometer (Screening tool)	Distress	Self-report	1 thermometer plus 50 item problem list	Problem categories: Practical Family Emotional Spiritual/religious Physical	Patients rate their distress over the past week on a thermometer from 0 to 10. Yes/no responses to all items in the problem list	Higher scores = greater distress	≥4
Richter et al. 2015[26] Adult cancer patients were recruited from 2 cancer wards in a cancer centre in Hamburg over 16 months	Research	34 young adults, 148 middle aged adults, 88 elderly	Young adults= 18-39, Middle aged= 40-65, Elderly= 66-88	Hematologic Mesothelial Urological Lung Gastrointestinal Gynaecological Head and neck Breast Other	German	Measure of Patients' Preferences (MPP) (German validated version) (Screening tool)	Patient physician communication preferences	Not stated	46 plus unstated number of additional questions added by the research team	Profession expertise/patient orientation, Emotional support, Comprehensive explanation, Clarity/directness, Family involvement, Information about psychosocial support,	46 items were rated on a scale from 1 (not at all) to 5 (essential). Overall satisfaction was rated on a 7-point scale from very dissatisfied to very satisfied	For each subscale an index was developed for the ratio of desired and fulfilled communication preferences from 0 to 100. A low index = high number of unconsidered desired	Not stated

Reference Setting (Inc. country)	Clinical v Researcl	Sample Size	Age Range	Cancer Diagnoses	Language	Screening Tool (Purpose of Measure)	Construct Being Measured	Mode of Administration	No. of Items	Subscales	Response Format	Scoring	Cutoff
										Sustainability, Privacy/confidentiality, Assessing the subjective need for information		communication preferences	
						German version of the National Comprehensive Cancer Network Distress Thermometer (Screening tool)	Distress	Not stated	1	None	Visual analogue scale from 0 (not distress) to 10 (extreme distresses)	Higher scores = greater distress	≥5 indicates distress that requires support
Palmer et al. 2014[27] This study carried out by CanTeen (Australia AYA cancer charity) developed the AYA Oncology Psychosocial Assessment and Care Process using a scoping review. Feedback on the tool was gained from clinicians and AYA cancer survivors	Research	Discussions about the tool were had with 11 AYA cancer survivors and 10 AYA clinicians	16-24	AYA cancer survivors involved in the discussion had a range of diagnoses including: Lung, Thyroid, Hodgkin's lymphoma, Ewing's sarcoma, Acute lymphoblastic leukaemia, Testicular	English	AYA Oncology Psychosocial Screening Tool (Screening tool)	Distress and information provision	Discussion around a tool- no administration	Not stated	Distress thermometer, Areas of concern, Information Provision	Distress thermometer, checklist for areas of concerns and a tick box for information provision	Not stated	Not stated
						AYA Oncology Psychosocial Assessment Measure (Screening tool)	Psychosocial assessment	Discussion around a tool- no administration	Not stated	Not stated	Used the HEADSS assessment revised for AYA cancer. Areas included strengths, other areas of life apart from diagnosis and implications of survivorship	Not stated	Not stated
Berard et al. 1998[28] Clinicians from a large general Hospital in Cape	Research	43	7-19 categorised into 12-14, 15-17, 18-19 years	Haematological, Sarcomas, Central nervous system, Dermatological, Miscellaneous disease sites	English	William Slater Centre (WSC) Assessment Form (Screening tool)	Psychiatric disorders and psychosocial history	Clinician led semi-structured interview	Not stated	Depressive symptoms, Suicidal ideation and parasuicide, Eating disorders, Substance abuse,	Not stated	Not stated	Not stated

Reference Setting (Inc. country)	Clinical v Researcl	Sample Size	Age Range	Cancer Diagnoses	Language	Screening Tool (Purpose of Measure)	Construct Being Measured	Mode of Administration	No. of Items	Subscales	Response Format	Scoring	Cutoff
Town, South Africa recruited newly diagnosed adolescents with cancer from the haematology and radiotherapy department										Psychosexual history, Sexual abuse and physical abuse, DSM-IV diagnosis			
						Hospital Anxiety and Depression Scale (HADS) (Screening tool)	Anxiety and depression	Self-report	Not stated	Not stated	Not stated	Not stated	8+
						Beck Depression Inventory (BDI) (Screening tool)	Depression	Self-report	Not stated	Not stated	Not stated	Not stated	16+
						Rotterdam Symptom Checklist (RSCL) (Screening tool)	Symptom burden	Self-report	Not stated	Not stated	Not stated	Not stated	11+
Muzzatti et al. 2020[29] Participants were recruited from a cancer institute in north-east Italy. It was a consecutive sample of patients undergoing surgery for breast cancer	Research	106	18-45	Breast	Italian	Short Form 36 Health Survey Questionnaire (SF-36) (Outcome)	Quality of life	Paper self-report	36	Physical Functioning, Role-Physical Limitation, Bodily Pain, General Health, Vitality, Social Functioning, Role-Emotional Limitation, Mental Health	Not stated	Physical Functioning, Role-Physical Limitation, Bodily Pain and General Health were categorised as the Physical Component Summary (PCS) and Vitality, Social Functioning, Role-Emotional Limitation and Mental Health were categorised as the Mental Component Summary (MCS). In each category raw scores were converted to t-	Not stated

Reference Setting (Inc. country)	Clinical v Researcl	Sample Size	Age Range	Cancer Diagnoses	Language	Screening Tool (Purpose of Measure)	Construct Being Measured	Mode of Administration	No. of Items	Subscales	Response Format	Scoring	Cutoff
												scores and higher scores = better functioning	
						Hospital Anxiety and Depression Scale (HADS) (Outcome)	Anxiety and depression	Paper self-report	14	Anxiety Depression	Not stated	In each subscale higher scores = greater anxiety/depression	Not stated
Soleimani et al. 2021[30] The sample consisted of patients the British Columbia Centre, Canada between April 2011 and 2015 who completed the pre-consultation health assessment form	Clinical	227 AYA 122 non-AYA	AYA = 18-39 Non-AYA = 40+	Germ cell tumours	English but interpreters could be used	PsychoSocial Screen for CANcer-Revised (PSSCAN-R) (Screening tool)	Psychological distress	Self-report	21	Anxiety Depression	5-point Likert scale	Percentages reporting symptoms were reported	Not stated
						Canadian Problem Checklist (CPC) (Screening tool)	Psychological distress	Self-report	Not stated	Emotional Informational Practical Spiritual Social Physical	Checklist	Percentages reporting symptoms were reported	Not stated
Rosenberg et al. 2018[31] Consecutive AYA participants were recruited from two hospitals in Boston and Seattle, US as part of the "Resilience in	Research	37 AYAs 40 parents	14-25	Non-central nervous system cancer requiring chemotherapy	English	Kessler-6 psychological distress scale (Predictor/outcome)	Psychological distress	Self-report	6	Not stated	Not stated	Higher scores = higher distress	Distress was categorised as low (0–3), moderate (4–6), high (7–12), or serious (>12)
						Dispositional Hope Tool (no official name given) (Predictor/outcome)	Dispositional hope	Self-report	Not stated	Agency (ability to generate a route to goals), Pathway (ability to initiate and maintain actions to reach goals)	Not stated	Higher scores = greater dispositional hope	Not stated

Reference Setting (Inc. country)	Clinical v Researcl	Sample Size	Age Range	Cancer Diagnoses	Language	Screening Tool (Purpose of Measure)	Construct Being Measured	Mode of Administration	No. of Items	Subscales	Response Format	Scoring	Cutoff
Adolescents and Young Adults with Cancer" (RAYA) study						PedsQL 3.0 Cancer Module (Outcome)	Cancer-related quality of life	Self-report	Not stated	Not stated	Not stated	Higher scores = greater cancer-related quality of life	Not stated
Zebrack et al. 2014[32] Participants were recruited from 3 institutions between March 2008 and April 2010 by monitoring clinical rosters for eligible patients. Country was not stated but the US is assumed from researchers backgrounds	Research	215	15-39	First diagnosis of any form of invasive cancer	English and Spanish	Brief Symptom Inventory-18 (BSI-18) (Screening tool)	Distress symptoms	Self-report	18	Depressive symptoms, Somatic distress, Anxiety symptoms	Participants responded to how much they had been bothered by distress symptoms over the past 7 days on a 5-point Likert scale from 0 (not at all) to 4 (extreme)	Age and gender adjusted t-scores were calculated for each subscale and for an overall Global Symptom Index (GSI). Higher scores = greater levels of distress	≥63 on GSI, or a ≥63 on two of three subscales indicates clinically significant distress or 'caseness'
						Service Use and Unsatisfied Need (Screening tool)	AYA expressed needs for information, counselling and practical support services	Self-report	15	Information and informational services, Emotional support services, Practical support services	Participants indicate which of 15 services they: 'Have used and would like to use more', 'Have used and have no further need', 'Have NOT used but would like to', and 'Have NOT used and have no need'	Scores of unsatisfied needs were created for each subscale and by counting the number of items at baseline. Each subscale score ranged from 0 to 5. Higher scores = greater unsatisfied need	Not stated
Wu et al. 2007[33] Participants were recruited through convenience sampling from 20 institutions in the US.	Research	Off therapy survivors= 226, patients on therapy= 136, healthy controls= 134	13-20	On therapy patients (received treatment for two or more months): Leukaemia, Lymphoma, Brain tumours, Other solid tumours	English	Minneapolis-Manchester Quality of Life Tool Adolescent Form (MMQL) (Screening tool)	Quality of life	Paper self-report	46	Quality of life domains: Physical functioning, Cognitive functioning, Psychological functioning, Body image, Social functioning,	Not stated	Overall quality of life was calculated by finding the average score which ranged from 1-5. Higher scores = minimal negative impact and greater health	Not stated

Reference Setting (Inc. country)	Clinical v Researcl	Sample Size	Age Range	Cancer Diagnoses	Language	Screening Tool (Purpose of Measure)	Construct Being Measured	Mode of Administration	No. of Items	Subscales	Response Format	Scoring	Cutoff
Clinicians gave permission for the study to contact their patients and parents										Intimate relations, Outlook on life		relater quality of life	
Hedstrom et al. 2006[34] Data was collected from patients 4-8 weeks post diagnosis from 3 paediatric oncology services in Sweden between February 1999 in Uppsala/March 2000 in Lund and Umea until September 2003	Research	53	13-19	CNS-tumour Ewing sarcoma Leukaemia Lymphoma Osteosarcoma Other	Swedish	Interview for disease and treatment distress (no official name) (Screening tool)	Disease and treatment related distress	Semi-structured interview with TYAs and nurses caring for them	20	Physical concerns, Personal changes, Feelings of alienation, Disease and treatment- related worries	Presence and levels of distress were identified on a 6-point scale from 0 (not at all) to 5 (very much). For four presence/absence questions yes/no answers were given. Nurses/physicians were asked the same questions to gain their perception of the adolescent's distress however, they had the option to answer 'don't know'	Not stated	Not stated
						Hospital Anxiety and Depression Scale (HADS) (Screening tool)	Anxiety and depression	Self-report and staff version given to nurses/physicians	14	Anxiety Depression	Answers were given on a 4-point scaled from 0 to 3	Scores on each subscale ranged from 0 (no distress) to 21 (maximum distress)	≥9 indicated clinical anxiety ≥7 indicated clinical depression
Guleria et al. 2021[35] Observational study carried out on all children and	Research	Age 1-10= 52, Age 11-20=42, Age 21-30=200, Age 31-40= 277	2-39	CNS tumours, Carcinomas, Hodgkin lymphoma, Undifferentiated/embryonal tumours,	English	National Comprehensive Cancer Network (NCCN) distress thermometer and problem list (Screening tool)	Distress	Self-report given to AYAs, children ≥12 years and parents of children <12 years	1 thermometer and 39 item problem list	Problem list: Practical problems Family Emotional Spiritual Physical problems	The thermometer was measured on a scale from 0 (no distress) to 10 (extreme distress)	Higher scores = greater distress	≥4 indicated distress

Reference Setting (Inc. country)	Clinical v Researcl	Sample Size	Age Range	Cancer Diagnoses	Language	Screening Tool (Purpose of Measure)	Construct Being Measured	Mode of Administration	No. of Items	Subscales	Response Format	Scoring	Cutoff
AYAs newly diagnosed with cancer in a cancer hospital in North India between April 2017 to March 2019				Non-Hodgkin lymphoma, Bone tumours, Ewing's sarcoma, Soft tissue sarcomas, Seminoma, NSGCT, GTN, Melanoma, Neuroendocrine tumours, Wilms' tumour		European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ C-30) (Screening tool)	Quality of life	Self-report for those >12	30	Day to day functionality, Symptoms	Participants responded on a 4-point scale (1= not at all, 2= a little bit, 3= quite a bit, 4= very much). Participants rated their overall physical health and quality of life on a scale from 0 to 10	Scores were summed for each subscale and ranged from 14 to 56	Not stated
Sender et al. 2019[36] Participants were recruited through 16 oncology acute care hospitals, 4 cancer rehabilitation centres and 2 cancer registries in Germany. They could also register to take part in the study from flyers and posters found on the project's website or social media	Research	514	18-39	First cancer diagnosis which included all malignant tumour identities	German	German version of the Supportive Care Needs Survey-Short Form (SCNS-SF34G) (Screening tool)	Supportive care needs	Paper or electronic self-report	34	Domains of needs: Psychological, Health system/information, Physical/daily living, Patient care/support, Sexuality	Level of need over the last week was reported on a 5-point Likert scale from 1 (no need) to 5 (high need). 2 AYA relevant items were added (fertility and desire to have children) which were responded to on the same scale	Items for each subscale were summed and scaled on a 0-100 range. Higher scores = greater unmet need	Not stated
						German version of the Distress Thermometer (Screening tool)	Distress	Paper or electronic self-report	1	None	Visual analogue scale from 0 (no distress) to 10 (extreme distress)	Higher scores = greater distress	≥5 indicates clinically significant distress
						Perceived Adjustment to Illness Scale (PACIS) (Screening tool)	Coping with the disease	Paper of electronic self-report	1	None	Participants rate on a scale from 0 (none) to 100 (great deal) 'How much effort does it cost you to cope with your illness?'	Higher scores = greater cost of coping with the illness	Not stated

Reference Setting (Inc. country)	Clinical v Researcl	Sample Size	Age Range	Cancer Diagnoses	Language	Screening Tool (Purpose of Measure)	Construct Being Measured	Mode of Administration	No. of Items	Subscales	Response Format	Scoring	Cutoff
Dawson et al. 2018[37] Retrospective study of young adults treated at City of Hope National Medical centre, US between 2009 and 2014 who completed the measures before treatment on their first/second visit to the centre	Clinical	630	18-39	Breast, Gynaecological, Genitourinary, Haematological, Gastrointestinal, Lung/Respiratory system, Brain and nervous system, Head and neck, Multi, Others, Unknown	English and Spanish	You, Your Family, and the City of Hope are a Team (Screening tool)	Biopsychosocial problem related distress	Electronic self-report	30 core items were used from the 53 item measure (it can be customised for disease-specific needs)	Types of wellbeing: Practical Physical Functional Emotional Social	Patients reported distress on a 5-point scale from 0 (not a problem) to 5 (very severe problem). Patients are then asked: 'How can we best work with you on this problem?' with options: Talk with a Member of the Team (coded as Talk), Provide Written Information (coded as Written), Nothing Needed at this Time (coded as None), or Both Written Information and Talk with Team Member (coded as Both)	Distress ratings were recorded with scores 1-2 indicating low distress, 3-5 indicating high distress	1-2 indicating low distress, 3-5 indicating high distress
Mandrell et al. 2011[8] Participants were adolescents from 4 oncology centres in the US who participated in 1 of 9 studies in which the FS-A was used to	Research	138 adolescents and their parents	13-18	ALL AML HL/lymphoma Solid tumour Germ cell tumour	English	The Fatigue Scale–Adolescent instrument for 13- to 18-year old children- (Revised 13-item FS-A) (Screening tool)	Cancer-related fatigue	Self-report	13	Not stated	Participants responded on a 5-point Likert scale	Scores ranged from 13 (no fatigue) to 65 (highest possible score). Higher scores = greater fatigue	31

Reference Setting (Inc. country)	Clinical v Researcl	Sample Size	Age Range	Cancer Diagnoses	Language	Screening Tool (Purpose of Measure)	Construct Being Measured	Mode of Administration	No. of Items	Subscales	Response Format	Scoring	Cutoff
measure fatigue													
McGrady et al. 2022[9] Two phase study to develop and validate the Multidimensional Psychosocial Assessment Strategy for Young Adults with Cancer. Phase 1- cognitive interviews with young adults recruited from a Midwestern children's hospital, US. Phase 2- the measure was evaluated on cancer survivors recruited from 2 Midwestern children's hospitals	Research	Phase 1- 20 (12 survivors, 8 active treatment) Phase 2- 100 at visit 1 and 90 at visit 2	18-39	Lymphoma, Bone sarcomas, Leukaemia, Soft tissue sarcomas, Central nervous system tumours	English	Young Adult—Psychosocial Assessment (Screening tool)	Psychosocial functioning	Electronic self-report	67	Anxiety, Depression, Cognitive functioning, Post-traumatic stress, Family stressors, Support, Social isolation, Self-efficacy for symptom management, Self-efficacy for medication management	Subscale items determined the presence/absence of clinical need. Three areas (resources, educational/vocational status, and relationship status) were assessed by options that could not be scored (e.g. multiple choice questions)	Total scores were calculated for each subscale and non-scoring questions were used for the remaining 3 areas	Anxiety ≥11, Depression ≥11, Cognitive Functioning ≤11, Post-Traumatic Stress ≥4, Family Stressors ≥4, Support ≤7, Social Isolation ≥14, Symptom Management ≤ 11, Medication Management ≤14
						National Comprehensive Cancer Network's Distress Thermometer (Validation tool)	Distress	Electronic self-report	1	None	Participants rate their distress over the past week on a scale of 0 (no distress) to 10 (extreme distress)	Higher scores = greater distress	Not stated
						PROMIS Scale v1.2- Global Mental 2a (Validation tool)	Global mental health	Electronic self-report	2	Not stated	Not stated	Not stated	Not stated
						Short Form Survey of Health-Related Quality of Life (SF-36) (Validation tool)	Health related quality of life	Electronic self-report	36	Not stated	Not stated	Not stated	Not stated
						Adolescent and Young Adult Service Use Questionnaire/Needs Assessment (Validation tool)	Supportive care needs	Electronic self-report	16	Not stated	Participants were assessed on the degree to which they have used or would like to use psychosocial services	Not stated	Not stated

Reference Setting (Inc. country)	Clinical v Researcl	Sample Size	Age Range	Cancer Diagnoses	Language	Screening Tool (Purpose of Measure)	Construct Being Measured	Mode of Administration	No. of Items	Subscales	Response Format	Scoring	Cutoff
						Social Support Survey (Validation tool)	Social support	Electronic self-report	19	Not stated	Not stated	An overall average was calculated to give the overall support index	Not stated
Hirayama et al. 2022[38] Two phase study that developed and assessed the feasibility of the Japanese version of the DTPL (DTPL-J). Phase 1- translation and back translation of the tool was carried out and semi-structured interviews took place with AYAs. Phase 2- feasibility assessed over 3 months at the National Cancer Centre Hospital (NCCH), Japan. Nurses assessed patients on admission using the tool	Research	Phase 1- 40 Phase 2- 230 AYAs completed the measure at least once	15-39	Phase 1: Bone and soft tissue tumour, Haematological, Lung, Breast, Melanoma, Head and neck, Gynaecological, Testicular, Renal Phase 2: Bone and soft tissue tumour, Haematological, Germ cell tumour, Colorectal, Gynaecological, Other	Japanese	Japanese version of the NCCN's Distress Thermometer and Problem List (DTPL) (Screening tool)	Distress	Self-report	1 thermometer and 49 item problem list	Practical problems, Family problems, Emotional problems, Spiritual or religious concerns, Physical problems	Distress was rated on a scale from 0 (no distress) to 10 (extreme distress)	Higher scores = greater distress	≥4 indicates clinically significant distress

Table 4. 'Hughes Quality Assessment Tool'

	Conceptual and measurement model:			**Reliability:**					**Validity:**					**Interpretability:**		**Methods of administration:**	**Cultural and language adaptations:**	
	Was the concept to be measured clearly defined? (Not defined=ND, Partially defined= PD, Fully defined=FD)	Was the population the measure was intended for adequately described? (Adequately described=AD, Partially described=PD, Not described=ND)	If so, was this population TYA cancer? (Yes=Y, No=N, Not stated= NS, Not applicable= NA)	Was any comment made on reliability (Yes=Y, No=N)	Was internal consistency reported? (Yes=Y, No=N)	If so was a statistic reported? (Yes=Y, No=N, Not applicable=NA)	Was test-retest reliability reported? (Yes=Y, No=N)	If so was a statistic reported? (Yes=Y, No=N, Not applicable=NA)	Was any comment made on validity (Yes=Y, No=N)	Was construct validity reported? (Yes=Y, No=N)	If so was a statistic reported? (Yes=Y, No=N, Not applicable=NA)	Was convergent validity reported? (Yes=Y, No=N)	If so was a statistic reported? (Yes=Y, No=N, Not applicable=NA)	Was a clear explanation given to allow interpretability of scores? (Very clear= VC, Partially clear =PC, Not clear=NC, Not stated=NS)	Were cut-off points given? (Yes=Y, No=N)	Was the method of administration mentioned? (Yes=Y, No=N)	Was the measure translated into another language? (Yes=Y, No=N, Not stated=NS)	If so, was there an evaluation of this measure's properties in the translated language? (Yes=Y, No=N, Not applicable= NA)
Kessler Psychological Distress Scale (K10) (Glidden et al. 2022)[10]	FD	AD	NS	N	N	NA	N	NA	Y	N	NA	N	NA	VC	Y	Y	Y	N
Research survey entitled: "Impact of COVID-19 Pandemic on Adolescents and Young Adults with Cancer in Canada" (Glidden et al. 2022)[10]	FD	ND	NA	N	N	NA	N	NA	N	N	NA	N	NA	PC	N	Y	Y	N
Distress screening questionnaire (Kivlighan et al. 2022)[11]	FD	ND	NA	N	N	NA	N	NA	N	N	NA	N	NA	VC	N	Y	N	NA

Distress thermometer-Chinese version (Duan et al. 2021)[12]	FD	AD	N	N	N	NA	N	NA	Y	N	NA	N	NA	VC	Y	Y	Y	Y
Three-dimensional inventory of character strengths (Duan et al. 2021)[12]	FD	PD	N	Y	Y	Y	N	NA	Y	N	NA	N	NA	VC	N	Y	Y	N
Medical coping modes questionnaire (Duan et al. 2021)[12]	FD	ND	NA	Y	Y	N	N	NA	Y	N	NA	N	NA	VC	N	Y	Y	N
Social Support Rating Scale (Duan et al. 2021)[12]	FD	AD	N	Y	N	NA	N	NA	Y	N	NA	N	NA	VC	N	Y	Y	N
Patient health questionnaire (PHQ-8) (Jacobson et al. 2022)[13]	FD	AD	N	Y	Y	Y	N	NA	Y	N	NA	N	NA	PC	Y	Y	N	NA
Generalised Anxiety Disorder Scale (GADS-7) (Jacobson et al. 2022)[13]	FD	AD	N	Y	N	NA	N	NA	Y	N	NA	N	NA	PC	Y	Y	N	NA
COVID-19 questionnaire (no name given) (Jacobson et al. 2022)[13]	FD	AD	Y	N	N	NA	N	NA	N	N	NA	N	NA	NC	NC	Y	N	NA
Connor–Davidson Resilience Scale (CD-RISC) (Jacobson et al. 2022)[13]	FD	PD	N	Y	N	NA	N	NA	Y	N	NA	N	NA	PC	N	Y	N	NA
PHQ2 (Giberson et al. 2021)[14]	FD	ND	NA	N	N	NA	N	NA	N	N	NA	N	NA	VC	Y	Y	N	NA
PHQ9 (Giberson et al. 2021)[14]	FD	ND	NA	N	N	NA	N	NA	N	N	NA	N	NA	VC	Y	Y	N	NA
Functional Assessment of Cancer Therapy-Cognitive Function (FACT-Cog) version 3 (Tan et al. 2020)[15]	FD	PD	N	Y	Y	Y	N	NA	Y	N	NA	N	NA	PC	N	Y	NS	NA
Distress Thermometer and problem checklist (Tan et al. 2020)[15]	FD	AD	N	N	N	NA	N	NA	Y	N	NA	N	NA	PC	Y	Y	NS	NA
Rotterdam Symptom Checklist (RSCL) (Tan et al. 2020)[15]	FD	AD	N	N	N	NA	N	NA	Y	N	NA	N	NA	PC	Y	Y	NS	NA

Canadian Problem Checklist (CPC) (Smrke et al. 2020)[16]	FD	ND	NA	N	N	NA	N	NA	N	N	NA	N	NA	PC	N	N	N	NA
PsychoSocial Screen for Cancer- Revised [PSSCAN-R] (Smrke et al. 2020)[16]	FD	AD	N	N	N	NA	N	NA	Y	N	NA	Y	N	VC	Y	N	N	NA
Social Network and Support Assessment tool (Smrke et al. 2020)[16]	FD	PD	N	N	N	NA	N	NA	N	N	NA	N	NA	PC	N	N	N	NA
PSSCAN-R (Naik et al. 2020)[18]	FD	PD	NS	Y	Y	Y	N	NA	Y	N	NA	N	NA	VC	Y	Y	N	NA
Canadian Problem Checklist (Naik et al. 2020)[18]	FD	PD	NS	N	N	NA	N	NA	N	N	NA	N	NA	PC	N	Y	N	NA
Patient Health Questionnaire (PHQ-9) (Geue et al. 2018)[19]	FD	ND	NA	Y	N	NA	N	NA	Y	Y	N	N	NA	VC	Y	Y	Y	N
General Anxiety Disorder-Scale (GAD-7) (Geue et al. 2018)[19]	FD	ND	NA	Y	N	NA	N	NA	Y	Y	N	N	NA	VC	Y	Y	Y	N
Distress thermometer (Chan et al. 2018)[20]	FD	AD	N	N	N	NA	N	NA	Y	N	NA	N	NA	VC	Y	Y	N	NA
Rotterdam Symptom Checklist (Chan et al. 2018)[20]	FD	PD	NS	N	N	NA	N	NA	Y	N	NA	Y	N	PC	N	Y	N	NA
PedsQL Generic Core Scales (Chan et al. 2018)[20]	FD	AD	Y	Y	Y	N	N	NA	Y	N	NA	N	NA	VC	N	Y	N	NA
Distress Thermometer (Xie et al. 2017)[21]	FD	AD	N	N	N	NA	N	NA	Y	N	NA	N	NA	VC	Y	Y	Y	Y
Hospital Anxiety and Depression Scale (Xie et al. 2017)[21]	FD	ND	NA	Y	N	NA	N	NA	Y	N	NA	N	NA	PC	Y	Y	Y	Y
Medical Coping Modes Questionnaire (Xie et al. 2017)[21]	FD	ND	NA	Y	N	NA	N	NA	Y	N	NA	N	NA	PC	N	Y	Y	Y
Social Support Rating Scale (Xie et al. 2017)[21]	FD	AD	N	Y	N	NA	N	NA	Y	N	NA	N	NA	VC	N	Y	Y	N
Information sheet (Sun et al. 2019)[22]	FD	AD	Y	N	N	NA	N	NA	N	N	NA	N	NA	PC	N	N	N	NA
Fear of Progression Questionnaire-Short Form (FoP-Q-SF) (Sun et al. 2019)[22]	FD	PD	NS	Y	Y	Y	N	NA	Y	N	NA	N	NA	VC	Y	N	Y	Y

General Anxiety Disorder Questionnaire (GAD-7) (Sun et al. 2019)[22]	FD	ND	NA	Y	Y	Y	N	NA	N	N	NA	N	NA	VC	Y	N	Y	Y
Patient Health Questionnaire (PHQ-9) (Sun et al. 2019)[22]	FD	PD	N	Y	Y	Y	N	NA	N	N	NA	N	NA	VC	Y	N	Y	Y
AYA Oncology Psychosocial Assessment Measure (Chalmers et al. 2018)[23]	FD	AD	Y	N	N	NA	N	NA	N	N	NA	N	NA	NS	N	Y	N	NA
Youth Satisfaction Questionnaire (Chalmers et al. 2018)[23]	FD	PD	Y	Y	Y	N	N	NA	N	N	NA	N	NA	PC	N	Y	N	NA
Kessler Psychological Distress Scale 10 (Chalmers et al. 2018)[23]	FD	ND	NA	N	N	NA	N	NA	N	N	NA	N	NA	PC	Y	Y	N	NA
Pediatric Quality of Life Inventory for adolescents and young adults (Chalmers et al. 2018)[23]	FD	AD	Y	N	N	NA	N	NA	N	N	NA	N	NA	PC	N	Y	N	NA
Posttraumatic Stress Symptoms. The Posttraumatic Stress Disorder Checklist (PCL-S) (McCarthy et al. 2016)[24]	FD	ND	NA	Y	Y	Y	N	NA	N	N	NA	N	NA	PC	Y	Y	N	NA
Kessler Psychological Distress Scale (K10) (McCarthy et al. 2016)[24]	FD	ND	NA	Y	Y	Y	N	NA	N	N	NA	N	NA	PC	N	Y	N	NA
The Multidimensional Scale of Perceived Social Support (MSPSS) (McCarthy et al. 2016)[24]	FD	ND	NA	Y	Y	Y	N	NA	N	N	NA	N	NA	NS	NS	Y	N	NA
Medical Outcomes Social Support Survey (MOS) (McCarthy et al. 2016)[24]	FD	ND	NA	Y	Y	Y	N	NA	N	N	NA	N	NA	NS	NS	Y	N	NA
Life Impact scale (modified to assess cancer impacts relevant to AYAs e.g., self-identity, confidence, future vocation, education, and family plans) (McCarthy et al. 2016)[24]	FD	AD	Y	N	N	NA	N	NA	N	N	NA	N	NA	PC	N	Y	N	NA

''Are there other life stresses that you feel have affected how you have been able to cope with your (or your son or daughter's) cancer diagnosis or treatment?'' (McCarthy et al. 2016)[24]	FD	ND	NA	N	N	NA	N	NA	N	N	NA	N	NA	NS	N	Y	N	NA
Distress Thermometer (Burgoyne et al. 2015)[25]	FD	AD	N	Y	N	NA	N	NA	Y	N	NA	N	NA	VC	Y	Y	N	NA
Measure of Patients' Preferences (MPP) (German validated version) (Richter at al. 2015)[26]	FD	ND	NA	N	Y	Y	N	NA	Y	N	NA	N	NA	VC	N	N	Y	N
German version of the National Comprehensive Cancer Network Distress Thermometer (Richter et al. 2015)[26]	FD	PD	NS	N	N	NA	N	NA	N	N	NA	N	NA	VC	Y	N	Y	N
WSC Assessment Form (Berard et al. 1998)[39]	FD	ND	NA	N	N	NA	N	NA	N	N	NA	N	NA	NC	N	Y	N	NA
Hospital Anxiety and Depression Scale (HADS) (Berard et al. 1998)[39]	ND	PD	NS	N	N	NA	N	NA	Y	N	NA	N	NA	NC	Y	Y	N	NA
Beck Depression Inventory (BDI) (Berard et al. 1998)[39]	FD	AD	N	N	N	NA	N	NA	N	N	NA	N	NA	NC	Y	Y	N	NA
Rotterdam Symptom Checklist (RSCL) (Berard et al. 1998)[39]	ND	PD	NS	N	N	NA	N	NA	Y	N	NA	N	NA	NC	Y	Y	N	NA
Short Form 36 Health Survey Questionnaire (SF-36) (Muzzatti et al. 2020)[29]	FD	PD	N	N	N	NA	N	NA	N	N	NA	N	NA	PC	N	Y	Y	Y
Hospital Anxiety and Depression scale (HADS) (Muzzatti et al. 2020)[29]	FD	ND	NA	N	N	NA	N	NA	N	N	NA	N	NA	PC	N	Y	NS	NA
PsychoSocial Screen for CANcer-Revised (PSSCAN-R) (Soleimani et al. 2021)[30]	FD	PD	NS	N	N	NA	N	NA	Y	N	NA	N	NA	NC	N	Y	N	NA
Canadian Problem Checklist (CPC) (Soleimani et al. 2021)[30]	FD	PD	NS	N	N	NA	N	NA	N	N	NA	N	NA	PC	N	Y	N	NA

Kessler-6 psychological distress scale (Rosenberg et al. 2018)[31]	FD	ND	NA	N	N	NA	N	NA	Y	N	NA	N	NA	PC	Y	Y	N	NA
Dispositional Hope Tool (Rosenberg et al. 2018)[31]	FD	ND	NA	N	N	NA	N	NA	Y	N	NA	N	NA	PC	N	Y	N	NA
PedsQL 3.0 Cancer Module (Rosenberg et al. 2018)[31]	FD	PD	NS	N	N	NA	N	NA	Y	N	NA	N	NA	PC	N	Y	N	NA
Brief Symptom Inventory-18 (BSI-18) (Zebrack et al. 2014)[32]	FD	AD	N	Y	Y	Y	N	NA	Y	N	NA	N	NA	VC	Y	N	Y	N
Service use and unsatisfied need (Zebrack et al. 2014)[32]	FD	AD	Y	N	N	NA	N	NA	N	N	NA	N	NA	VC	N	N	Y	N
Minneapolis-Manchester Quality of Life Tool Adolescent Form (MMQL) (Wu et al. 2007)[33]	FD	AD	Y	Y	Y	N	Y	N	Y	Y	N	N	NA	VC	N	Y	N	NA
Interview for disease and treatment distress (no official name) (Hedstrom et al. 2006)[34]	FD	ND	NA	N	N	NA	N	NA	N	N	NA	N	NA	VC	N	Y	N	NA
Hospital anxiety and depression scale (HADS) (Hedstrom et al. 2006)[34]	FD	AD	Y	Y	N	NA	Y	N	Y	N	NA	N	NA	VC	Y	Y	Y	N
National Comprehensive Cancer Network (NCCN) distress thermometer and problem list (Guleria et al. 2021)[35]	FD	PD	NS	N	N	NA	N	NA	N	N	NA	N	NA	VC	Y	N	N	NA
European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ C-30) (Guleria et al. 2021)[35]	FD	PD	NS	N	N	NA	N	NA	N	N	NA	N	NA	VC	N	N	N	NA
German version of the Supportive Care Needs Survey-Short Form (SCNS-SF34G) (Sender et al. 2019)[36]	FD	ND	NA	Y	Y	Y	N	NA	Y	N	NA	N	NA	VC	N	Y	Y	Y
German version of the Distress Thermometer (Sender et al. 2019)[36]	FD	AD	NS	Y	N	NA	N	NA	Y	N	NA	N	NA	VC	Y	Y	Y	Y

Perceived Adjustment to Illness Scale (PACIS) (Sender et al. 2019)[36]	FD	AD	NS	N	N	NA	N	NA	Y	N	NA	N	NA	VC	N	Y	Y	N
You, Your Family, and the City of Hope are a Team (Dawson et al. 2018)[37]	FD	PD	N	N	N	NA	N	NA	Y	N	NA	N	NA	VC	N	Y	Y	N

Table 5. COSMIN Quality Assessment Tool

		Worry/Learning Thermometer and checklist (Cuffe et al. 2022)[4]	Adolescent & Young Adult Psychosocial Oncology Screening Tool (Patterson et al. 2021)[5]	Cancer distress scales for adolescents and young adults (CDS-AYA) (Rae et al. 2020)[17]	Edmonton Symptom Assessment Scale-Revised (Rae et al. 2020)[17]	Distress thermometer (NCCN-DT) (Rae et al. 2020)[17]	Hospital anxiety and depression scale (Rae et al. 2020)[17]	Field test version of the Cancer Distress Scales for AYA (CDS-AYA) (Tsangaris et al. 2019)[7]	Cancer Distress Scales (CDS-AYA) (Rae et al. 2019)[6]	AYA Oncology Psychosocial Screening Tool (Palmer et al. 2014)[27]	AYA Oncology Psychosocial Assessment Measure (Palmer et al. 2014)[27]	The Fatigue Scale–Adolescent instrument for 13- to 18-year old children- (Revised 13-item FS-A) (Mandrell et al. 2011)[8]	Young Adult—Psychosocial Assessment (McGrady et al. 2022)[9]	Japanese version of the NCCN's Distress Thermometer and Problem List (DTPL) (Hirayama et al. 2022)[38]
PROM Development	PROM design													
	Cognitive interview/pilot-comprehensibility													
	Cognitive interview/pilot-comprehensiveness													
	Cognitive interview/pilot- total													
	PROM development total													

		Worry/Learning Thermometer and checklist (Cuffe et al. 2022)[4]	Adolescent & Young Adult Psychosocial Oncology Screening Tool (Patterson et al. 2021)[5]	Cancer distress scales for adolescents and young adults (CDS-AYA) (Rae et al. 2020)[17]	Edmonton Symptom Assessment Scale-Revised (Rae et al. 2020)[17]	Distress thermometer (NCCN-DT) (Rae et al. 2020)[17]	Hospital anxiety and depression scale (Rae et al. 2020)[17]	Field test version of the Cancer Distress Scales for AYA (CDS-AYA) (Tsangaris et al. 2019)[7]	Cancer Distress Scales (CDS-AYA) (Rae et al. 2019)[6]	AYA Oncology Psychosocial Screening Tool (Palmer et al. 2014)[27]	AYA Oncology Psychosocial Assessment Measure (Palmer et al. 2014)[27]	The Fatigue Scale–Adolescent instrument for 13- to 18-year old children- (Revised 13-item FS-A) (Mandrell et al. 2011)[8]	Young Adult—Psychosocial Assessment (McGrady et al. 2022)[9]	Japanese version of the NCCN's Distress Thermometer and Problem List (DTPL) (Hirayama et al. 2022)[38]
Content Validity	Asking patients about relevance													
	Asking patients about comprehensiveness													
	Asking patients about comprehensibility													
	Asking professionals about relevance													
	Asking professionals about comprehensiveness													
Structural validity														
Internal consistency														

		Worry/Learning Thermometer and checklist (Cuffe et al. 2022)[4]	Adolescent & Young Adult Psychosocial Oncology Screening Tool (Patterson et al. 2021)[5]	Cancer distress scales for adolescents and young adults (CDS-AYA) (Rae et al. 2020)[17]	Edmonton Symptom Assessment Scale-Revised (Rae et al. 2020)[17]	Distress thermometer (NCCN-DT) (Rae et al. 2020)[17]	Hospital anxiety and depression scale (Rae et al. 2020)[17]	Field test version of the Cancer Distress Scales for AYA (CDS-AYA) (Tsangaris et al. 2019)[7]	Cancer Distress Scales (CDS-AYA) (Rae et al. 2019)[6]	AYA Oncology Psychosocial Screening Tool (Palmer et al. 2014)[27]	AYA Oncology Psychosocial Assessment Measure (Palmer et al. 2014)[27]	The Fatigue Scale–Adolescent instrument for 13- to 18-year old children- (Revised 13-item FS-A) (Mandrell et al. 2011)[8]	Young Adult—Psychosocial Assessment (McGrady et al. 2022)[9]	Japanese version of the NCCN's Distress Thermometer and Problem List (DTPL) (Hirayama et al. 2022)[38]
Cross-cultural validity														
Reliability														
Measurement error														
Construct validity	Convergent validity													
	Discriminative or known groups validity													
Responsiveness	Comparison with other instruments													
	Comparison between subgroups													

		Worry/Learning Thermometer and checklist (Cuffe et al. 2022)[4]	Adolescent & Young Adult Psychosocial Oncology Screening Tool (Patterson et al. 2021)[5]	Cancer distress scales for adolescents and young adults (CDS-AYA) (Rae et al. 2020)[17]	Edmonton Symptom Assessment Scale-Revised (Rae et al. 2020)[17]	Distress thermometer (NCCN-DT) (Rae et al. 2020)[17]	Hospital anxiety and depression scale (Rae et al. 2020)[17]	Field test version of the Cancer Distress Scales for AYA (CDS-AYA) (Tsangaris et al. 2019)[7]	Cancer Distress Scales (CDS-AYA) (Rae et al. 2019)[6]	AYA Oncology Psychosocial Screening Tool (Palmer et al. 2014)[27]	AYA Oncology Psychosocial Assessment Measure (Palmer et al. 2014)[27]	The Fatigue Scale–Adolescent instrument for 13- to 18-year old children- (Revised 13-item FS-A) (Mandrell et al. 2011)[8]	Young Adult—Psychosocial Assessment (McGrady et al. 2022)[9]	Japanese version of the NCCN's Distress Thermometer and Problem List (DTPL) (Hirayama et al. 2022)[38]
	Comparison before and after intervention													

Key:

	Very good
	Adequate
	Doubtful
	Inadequate
	Not included

Table 6. Psychometric Properties Extracted Using COSMIN Guidelines

PROM (ref)	Country (language) in which the PROM was evaluated	Structural validity			Internal consistency (Cronbach Alpha)			Cross-cultural validity\ measurement invariance			Reliability		
		n	Meth qual	Result (rating)	n	Meth qual	Result (rating)	n	Meth qual	Result (rating)	n	Meth qual	Result (rating)
Worry Thermometer (Cuffe et al. 2022)[4]	UK (English)										549	I	Spearman rank correlations = 0.65, p < 0.001 Parent report: rs = 0.68, p < 0.001 (-)
Learning Thermometer (Cuffe et al. 2022)[4]	UK (English)										549	I	Spearman rank correlations = 0.7, p < 0.001 Parent report: rs = 0.82, p < 0.001 (+)
Cancer distress scales for adolescents and young adults (CDS-AYA) (Rae et al. 2020)[17]	Canada (English)				421	V	0.79-0.94 (CDS-AYA Emotional= 0.936, impact of cancer= 0.94) (+)	421	I	Males- females [mean diff (SE)]: Emotional: -6.2 (1.9), p<.001; impact of cancer: -5.1 (1.9), p<.01. Active treatment-completed: Emotional: 9.0(1.9), p<.001; impact of cancer: 16.6(1.8), p<.001 (?)	81% participants	D	CDS-AYA emotional- ICC 0.853 (p<.001) 95% CI (0.763, 0.908). CDS-AYA impact of cancer- ICC 0.855 (p<.001) 95% CI (0.768, 0.910) (+)
Edmonton Symptom Assessment Scale-Revised	Canada (English)				421	V	0.880 (+)	421	I	Males- females [mean diff (SE)]:-2.6 (1.4), p=0.068	81% participants	D	ICC 0.836 (p<.001), 95% CI (0.736, 0.898) (+)

PROM (ref)	Country (language) in which the PROM was evaluated	Structural validity			Internal consistency (Cronbach Alpha)			Cross-cultural validity\ measurement invariance			Reliability		
		n	Meth qual	Result (rating)	n	Meth qual	Result (rating)	n	Meth qual	Result (rating)	n	Meth qual	Result (rating)
(Rae et al. 2020)[17]										Active treatment-completed: 6.9(1.4), p<.001 (?)			
Distress thermometer (NCCN-DT) (Rae et al. 2020)[17]	Canada (English)							421	I	Males- females [mean diff (SE)]: -5.5 (0.24), p<.05 Active treatment-completed: 0.67 (0.24), p<.01 (?)	81% participants	D	ICC 0.728 (p<.001), 95% CI (0.562, 0.831) (+)
Hospital anxiety and depression scale (Rae et al. 2020)[17]	Canada (English)				421	V	HAS total 0.876; anxiety 0.851; depression 0.793 (+)	421	I	Males- females [mean diff (SE)]: HADS overall: -1.6 (0.67), p<.05; anxiety: -1.1 (0.41), p<.05; depression: -0.52 (0.35, p=0.133 Active treatment-completed: HADS overall: 2.7 (0.66), p<.001; anxiety: 0.84 (0.41), p<.05; depression: 1.8 (0.33), p<.001 (?)	81% participants	D	HADS overall- ICC 0.910 (p<.001), 95% CI (0.856, 0.944); anxiety- ICC 0.862 (p<.001), 95% CI (0.769, 0.916); depression- ICC 0.864 (p<.001), 95% CI (0.773, 0.917) (+)
Field test version of the Cancer Distress Scales for AYA (CDS-AYA)	Canada (English)	515	V	Rasch Measurement Theory showed 5 scales with validity/reliability: • Impact of cancer • Physical	515	V	Impact of cancer= 0.94; Physical= 0.85;	515	D	DIF was evident for age group (3 items; age groups = 15–19, 20–29, and 30–39), phase of treatment (3 items), and gender (3	86	I	ICCs: Impact of cancer= 0.85; Physical= 0.78; Emotional= 0.81;

PROM (ref)	Country (language) in which the PROM was evaluated	Structural validity			Internal consistency (Cronbach Alpha)			Cross-cultural validity\ measurement invariance			Reliability		
		n	Meth qual	Result (rating)	n	Meth qual	Result (rating)	n	Meth qual	Result (rating)	n	Meth qual	Result (rating)
(Tsangaris et al. 2019)[7]				• Emotional • Cancer worry • Cognitive No items had disordered thresholds and item fit was -2.5 for 41/48 items. Employment, education, practical and social scales had disordered thresholds, poor model fit and low reliability so were retained as checklists except for the social scale which was dropped. (-)			Emotional= 0.94; Cancer worry= 0.88; Cognitive =0.91 (+)			items). "Significant items were split by age, phase of treatment, and gender, and Pearson correlations between the original and split person locations showed that DIF had a negligible impact, with all correlations >0.99."[7](p.10) (+)			Cancer worry= 0.88; Cognitive =0.83 (+)
The Fatigue Scale–Adolescent instrument for 13- to 18-year old children-(Revised 13-item FS-A) (Mandrell et al. 2011)[8]	USA (English)	138	V	Mean Square fit (MnSq) coefficient for item 9 was unacceptable and was therefore removed. Confirmatory factor analysis for the 4-factor structure after the removal of item 9: goodness-of-fit index .8551, root mean square residual (RMSEA) .080. (-)	138	V	0.87 (+)						

PROM (ref)	Country (language) in which the PROM was evaluated	Structural validity			Internal consistency (Cronbach Alpha)			Cross-cultural validity\ measurement invariance			Reliability		
		n	Meth qual	Result (rating)	n	Meth qual	Result (rating)	n	Meth qual	Result (rating)	n	Meth qual	Result (rating)
Young Adult—Psychosocial Assessment (McGrady et al. 2022)[9]	USA (English)	64-98	I	RMSEA; CFI; TLI; SRMR; Anxiety: 0.19; 0.99; 0.96; 0.04 Depression: 0.13; 1.00; 0.99; 0.02 Cognitive functioning: 0.10; 1.00; 1.00; 0.01 Post-traumatic stress: 0.03; 0.99; 0.99; 0.08 Family stressors: 0.05; 0.96; 0.94; 0.11 Support: 0.16; 0.98; 0.95; 0.07 Social isolation: 0.08; 1.00; 1.00; 0.02 Self-efficacy for symptom management: 0.00; 1.00; 1.00; <0.01 Self-efficacy for medication management: 0.17; 0.98; 0.95; 0.04 Life stressors: 0.02; 0.99; 0.99; 0.10 (-)	100	V	Acceptable for all domains (range = 0.70–0.93) other than family stressors (0.59) (-)				90	I	Acceptable for all domains (rs = 0.69–0.87) other than medication management (0.58) (-)
Japanese version of the NCCN's Distress Thermometer and Problem List (DTPL)	Japan (Japanese)										41	I	Dealing with children (r = 0.787, p < 0.0001),

PROM (ref)	Country (language) in which the PROM was evaluated	Structural validity			Internal consistency (Cronbach Alpha)			Cross-cultural validity\ measurement invariance			Reliability		
		n	Meth qual	Result (rating)	n	Meth qual	Result (rating)	n	Meth qual	Result (rating)	n	Meth qual	Result (rating)
(Hirayama et al. 2022)[38]													Child care (r = 0.729, p < 0.0001), Ability to have children (r = 0.412, p < 0.0001), Dealing with partner (r = 0.498, p < 0.0001), Work or school (r = 0.641, p < 0.0001), Housing (r = 0.763, p < 0.0001). (-)

Table 7. Psychometric Properties of Measures Validated in Non-Cancer Populations

Measure	Population Validated In	Internal Consistency (Cronbach Alpha)	Test-Retest Reliability (Intraclass Correlation Coefficient)	Construct Validity [mean diff (SE)]	Sensitivity	Specificity
Strength and difficulties questionnaire (Cuffe et al. 2022)[4]	Paediatric chronic illness	0.73	-	-	-	-
Three-dimensional inventory of character strengths (Duan et al. 2021)[12]	Cross-population (community vs inpatients) and cross-cultural (Asian vs Western)	>0.74	-	-	-	-
Patient health questionnaire (PHQ-8) (Jacobson et al. 2022)[13]	Outpatient heart failure	0.82	-	-	-	-
Hospital anxiety and depression scale (Rae et al. 2020)[17]	General outpatient clinics (AYAs involved in the development but not cancer patients)	HADS overall= 0.876, HADS-A= 0.851, HADS-D = 0.793	HADS overall= 0.910 (p<.001), 95% CI (0.856, 0.944); HADS-A= 0.862 (p<.001), 95% CI (0.769, 0.916); HADS-D=0.864 (p<.001), 95% CI (0.773, 0.917)	Males-females: HADS overall= -1.6 (0.67), p<.05; HADS-A = -1.1 (0.41), p<.05; HADS-D = -0.52 (0.35, p=0.133 Active treatment-completed: HADS overall= 2.7 (0.66), p<.001; HADS-A = 0.84 (0.41), p<.05; HADS-D = 1.8 (0.33), p<.001	-	-
Psychosocial Screen for Cancer-Revised (PSSCAN-R) (Naik et al. 2020)[18]	Not stated	Anxiety= 0.83, Depression= 0.79	-	-	-	-
Hospital Anxiety and Depression Scale	Various populations	0.67–0.93	-	-	-	-

Measure	Population Validated In	Internal Consistency (Cronbach Alpha)	Test-Retest Reliability (Intraclass Correlation Coefficient)	Construct Validity [mean diff (SE)]	Sensitivity	Specificity
(HADS) (Tsangaris et al. 2019)[7]						
Patient Health Questionnaire (PHQ-9) (Geue et al. 2018)[19]	Not stated	-	-	-	87%	76%
German version of the Supportive Care Needs Survey-Short Form (SCNS-SF34G) (Sender et al. 2019)[36]	Not stated	0.82– 0.94	-	-	-	-

Table 8. Psychometric Properties of Measures Validated in Cancer Populations (Not Specific to TYA)

Measure	Population Validated In	Internal Consistency (Cronbach Alpha)	Test-Retest Reliability (Intraclass Correlation Coefficient)	Construct Validity [mean diff (SE)]	Sensitivity	Specificity
Hospital anxiety and depression scale (Cuffe et al. 2022)[4]	Adult oncology populations	HADS-D = 0.82, HADS-A = 0.83	-	-	-	-
Pediatric quality of life inventory (PedsQL) (Cuffe et al. 2022)[4]	Paediatric oncology	Self-report = 0.88, Parent proxy = 0.90	-	-	-	-
Distress thermometer-Chinese version (Duan et al. 2021)[12]	Chinese cancer patients	-	-	-	0.82	0.95
Functional Assessment of Cancer Therapy-Cognitive Function (FACT-Cog) version 3 (Tan et al. 2020)[15]	Asian breast cancer patients	>0.9 (item-to-scale correlation >0.7)	-	-	-	-
Edmonton Symptom Assessment Scale-Revised (Rae et al. 2020)[17]	Adults with advanced cancer (AYAs not excluded in the development but the process mainly involved older adults)	0.88	0.836 (p<.001), 95% CI (0.736, 0.898)	males-females -2.6 (1.4), p=0.068 Active treatment-completed 6.9 (1.4), p<.001	-	-
Distress thermometer (NCCN-DT) (Rae et al. 2020)[17]	Prostate cancer	-	0.728 (p<.001), 95% CI (0.562, 0.831)	males-females -5.5 (0.24), p<.05 Active treatment-completed 0.67 (0.24), p<.01	-	-
Distress Thermometer (Burgoyne et al. 2015)[25]	Adult cancer populations	-	-	-	Depression- 80.9% Anxiety-77.1%	Depression- 60.2% Anxiety-66.1%

Table 9. Psychometric Properties of Measures Validated in TYA Cancer Populations That Could Not be Quality Assessed Using COSMIN

Measure (Reference)	Age range of TYA cancer population that measure was validated in	Internal Consistency (Cronbach Alpha)	Sensitivity	Specificity
Fear of Progression Questionnaire-Short Form (FoP-Q-SF) (Sun et al. 2019)[22]	15-39	0.848	-	-
General Anxiety Disorder Questionnaire (GAD-7) (Sun et al. 2019)[22]	15-39	0.883	-	-
Patient Health Questionnaire (PHQ-9) (Sun et al. 2019)[22]	15-39	0.802	-	-
Posttraumatic Stress Symptoms. The Posttraumatic Stress Disorder Checklist (PCL-S) (McCarthy et al. 2016)[24]	15-25	AYAs = 0.91, Parents = 0.92	-	-
Kessler Psychological Dis- tress Scale (K10) (McCarthy et al. 2016)[24]	15-25	AYAs= 0.93 parents= 0.94	-	-
The Multidimensional Scale of Perceived Social Support (MSPSS) (McCarthy et al. 2016)[24]	15-25	0.94	-	-
Medical Outcomes Social Support Survey (MOS) (McCarthy et al. 2016)[24]	15-25	0.96	-	-
Hospital Anxiety and Depression Scale (HADS) (Berard et al. 1998)[39]	12-19	-	Case requiring further attention= 75%, Cases with depressive symptomology= 67%, DSM-IV diagnosis= 67%, DSM-IV depressed mood disorder= 50%	Case requiring further attention= 74%, Cases with depressive symptomology= 70%, DSM-IV diagnosis= 70%, DSM-IV depressed mood disorder= 67%
Beck Depression Inventory (BDI) (Berard et al. 1998)[39]	12-19	-	Case requiring further attention= 50%, Cases with depressive symptomology= 50%, DSM-IV diagnosis= 40%, DSM-IV depressed mood disorder= 33%	Case requiring further attention= 58%, Cases with depressive symptomology= 57%, DSM-IV diagnosis= 56%, DSM-IV depressed mood disorder= 41%
Rotterdam Symptom Checklist (RSCL) (Berard et al. 1998)[39]	12-19	-	Case requiring further attention= 63%, Cases with depressive symptomology= 83%, DSM-IV diagnosis= 50%,	Case requiring further attention= 89%, Cases with depressive symptomology= 89%, DSM-IV diagnosis= 84%,

Measure (Reference)	Age range of TYA cancer population that measure was validated in	Internal Consistency (Cronbach Alpha)	Sensitivity	Specificity
			DSM-IV depressed mood disorder= 75%	DSM-IV depressed mood disorder= 85%
Brief Symptom Inventory-18 (BSI-18) (Zebrack et al. 2014)[32]	15-39	0.90	-	-
Interview for disease and treatment distress (no official name) (Hedstrom et al. 2006)[34]	13-19	-	Physical concerns: Infections- physicians-59%, nurses-64%, Mucositis- 60%, 59%, Nausea- 71%, 79%, Pain from disease-71%, 44%, Pain from procedures/treatments-60%,62% Personal changes: Changed temper- 60%, 46%, Fatigue-84%, 80%, Hair loss-84%, 86%, Round face-52%, 67%, Weight loss/gain-49%, 76% Feelings of alienation: Experiencing lower self-esteem-0%, 33%, Feeling different than friends-73%, 40%, Feeling left-out by friends- 29%, 56%, Missing leisure activities- 60%, 100%, not wanting others to see me- 11%, 44% Disease- and treatment-related worries: Worry about being left-out by friends-0%, 57%,	Physical concerns: Infections- physicians-84%, nurses-61%, Mucositis- 83%, 83%, Nausea- 77%, 53%, Pain from disease-79%, 49%, Pain from procedures/treatments-57%,47% Personal changes: Changed temper- 17%, 46%, Fatigue-35%, 18%, Hair loss-67%, 100%, Round face-80%, 86%, Weight loss/gain-14%, 57% Feelings of alienation: Experiencing lower self-esteem-67%, 78%, Feeling different than friends-23%, 21%, Feeling left-out by friends- 39%, 2%, Missing leisure activities- 20%, 0%, not wanting others to see me- 69%, 73% Disease- and treatment-related worries: Worry about being left-out by friends-50%, 41%, Worry about changed appearance-36%, 38%,

Measure (Reference)	Age range of TYA cancer population that measure was validated in	Internal Consistency (Cronbach Alpha)	Sensitivity	Specificity
			Worry about changed appearance- 60%, 75%, Worry about pain from procedures/treatments- 45%, 69%, Worry about missing school- 25%, 53%, Worry not getting well- 79%, 76%	Worry about pain from procedures/treatments- 43%, 38%, Worry about missing school- 79%, 39%, Worry not getting well- 21%, 17%
Hospital anxiety and depression scale (HADS) (Hedstrom et al. 2006)[34]	13-19	Adolescents: HADS-A= 0.64, HADS-D= 0.56 Physicians: HADS-A= 0.82, HADS-D= 0.76 Nurses: HADS-A= 0.84, HADS-D= 0.75	Physicians: HADS-A= 75%, HADS-D= 56% Nurses: HADS-A= 60%, HADS-D= 50%	Physicians: HADS-A= 54%, HADS-D= 60% Nurses: HADS-A= 82%, HADS-D= 71%

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Chapter 2- Part 1

Empirical Project

The association of resilience with psychosocial outcomes in teenagers and young adults with cancer

Supervised by Dr Susie Henley, Dr Ewan Carr, & Dr Clare Jacobson

Table of Contents

Abstract

Purpose

There is limited research on the psychological impact of cancer for teenagers and young adults (TYAs) and the role of protective factors like resilience. This study investigated associations between resilience and psychosocial outcomes in this group.

Methods

Data were collected from TYAs (aged 16-24) who attended the TYA cancer clinic at Guy's Hospital between 2013 and 2021. Participants (N=63) completed psychosocial questionnaires within 4 weeks of their treatment start date (T_1) and again between 9 and 15 months later (T_2). We used separate multivariable linear regression models to analyse associations of resilience (Brief Resilience Questionnaire) with outcomes measured at T_2 including symptoms of depression (PHQ-9), anxiety (GAD-7), and subjective quality of life. Models were adjusted for age, gender, ethnicity, and T_1 outcome assessments.

Results

Higher resilience at T_1 was associated with increased anxiety (β = 1.68; Bootstrapped 95% CI [-0.28, 3.19]), depression (β = 1.24; [-0.85, 2.90]) and quality of life (β = 5.76; [-0.88, 15.60]). In contrast, an increase in resilience over time was associated with decreases in the same period in anxiety (β = -3.16; [-5.22, -1.47]) and depression (β = -2.36, [-4.41, -0.58]) and an increase in quality of life (β = 9.82, [-0.24, 21.13]).

Conclusion

Increases in resilience during cancer treatment were associated with reduced symptoms of depression and anxiety in TYAs. We discuss factors likely to influence these outcomes and the implications for psychosocial interventions in this population, as well as further research to explore the impact of other factors such as diagnosis and treatment type.

Introduction

A diagnosis of cancer can lead to many physical and psychosocial difficulties, but it is particularly challenging for teenagers and young adults (TYAs) due to disruptions of key developmental and transitional stages[1,2]. In the UK, TYAs are defined as individuals aged 16 to 24[3]. A diagnosis can cause problems with social relationships and self-identity, physical changes and infertility, and a fear of the cancer returning[4,5]. Many TYAs with cancer face interruptions to education or work that have financial implications, as well as a loss of purpose[2]. Therefore, greater reliance on families might be required which brings many interpersonal and emotional difficulties[6].

Understanding the psychological impact of a cancer diagnosis in TYAs is crucial to developing appropriate interventions that lead to better psychosocial outcomes[7]. So far there has been limited research into TYA cancer and most research has focused on paediatric or adult cancer[8]. However, it is known that TYAs have poorer outcomes compared to children and adults with increased levels of depression and anxiety and lower quality of life[9-11]. As well as research into this area being sparse, different organisations use varying definitions of TYA cancer with a wide age range reported throughout the literature[1,7,12]. Further research is needed focusing on psychosocial outcomes, such as anxiety and depression, for TYAs with cancer defined as ages 16 to 24.

A positive psychological approach that emphasises resilience is important for mental health and health outcomes more broadly. Resilience is defined as the ability to develop and use protective resources to cope with, adapt and bounce back from stressful experiences such as an illness[5,13]. Individual skills such as goal setting and cognitive reframing can be seen as resilience resources and resilience can positively impact both physical and mental wellbeing[14,15]. Therefore, the aim of the present study was to explore the association between resilience and psychosocial outcomes in TYAs with cancer.

It is unclear whether resilience is a stable construct or something that changes over time. Some literature suggests that resilience should be measured as a stable construct[13] and the Resilience in Illness Model (RIM) describes predictive factors such as social integration and courageous coping that contribute to positive adjustment to illness[5]. On the other hand,

other research has considered resilience as a changeable construct and suggests interventions to build resilience such as Promoting Resilience in Stress Management (PRISM) and the Resilience Enhancement for Adolescents and Young Adults with Cancer and Healthcare Providers (REACH) intervention[9,16]. We therefore measured resilience both before and during/after treatment in our study.

Aims and Hypotheses

Past studies provide some understanding of the role of resilience in psychosocial outcomes for TYAs with cancer. However, this research is limited due to the greater focus on paediatric and adult cancer. Most research has taken place outside of the UK with widely varying age ranges, making it hard to generalise to TYAs as defined in the UK. This paper investigated associations between resilience and psychosocial outcomes in TYA cancer defined as ages 16 to 24. The psychosocial outcomes were symptoms of depression and anxiety and self-rated quality of life. We explored associations of both initial resilience (around the start of treatment) as well as changes in resilience over time. We hypothesised that:

1. Higher levels of resilience within 4 weeks of the start of treatment (T_1) would be associated with better psychosocial outcomes 9 to 15 months later (T_2).
2. An increase in resilience from T_1 to T_2 would be associated with better psychosocial outcomes at T_2.

Materials and Methods

Participants

This study used a retrospective cohort study design. 361 TYAs with cancer (diagnosed between ages 16-24) attended the TYA Cancer Service at Guy's Hospital between 2013 and 2021. The data were collected as part of 'Integrating Mental and Physical Healthcare: Research, Training and Services' (IMPARTS)[17,18], a project designed to improve the integration of mental and physical healthcare. Participants were asked to complete questionnaires on an iPad or smartphone every time they attended the clinic (typically every 3 months). Data collected through IMPARTS included self-report psychosocial measures and

demographic and clinical information including age at screening, date of diagnosis and treatment status. Age at diagnosis, gender, ethnicity, diagnosis, treatment type and treatment start/end date were extracted from electronic patient records. When TYAs completed questionnaires as part of IMPARTS they were informed that their anonymised data might be used for research purposes and of their right to opt out at any time. The IMPARTS framework provides generic ethical approval for analysis of pseudo-anonymised data that has been routinely collected via the platform (REC Ref: 18/SC/0039).

Timepoints

We defined T_1 as the period within 4 weeks either side of the start of treatment. For TYAs that underwent successive different types of treatment (e.g. surgery followed by chemotherapy), start of treatment relates to their first treatment type. T_2 was defined as measures completed 9 to 15 months after T_1. Initial discussions with clinicians at the TYA Cancer Service at Guy's Hospital suggested that 12 months was a sufficient time period to see a reliable change[19] in outcomes. Since TYAs were typically invited to attend clinic every 3 months, a time frame of 9 to 15 months was used so as to fully encompass this period.

Measures

The independent variable was the Brief Resilience Scale (BRS)[20], a six-item scale that assesses an individual's ability to bounce back or to recover from stress. Participants are asked to indicate the extent to which they agree with each statement (e.g. "I tend to bounce back quickly after hard times"[20]) from 'strongly disagree' to 'strongly agree'. Three items are positively worded and three are negatively worded. The BRS was scored as per instructions by reverse coding the negative items and calculating the mean of all six items. Higher scores indicate higher levels of resilience. This scale has been shown to have good internal consistency and test-retest reliability in student and medical samples[13]. Previous measures of resilience focused on the personal characteristics that allowed for positive adaptation to challenging experiences whereas the BRS was the first measure developed to assess resilience in its basic meaning: to bounce back from stress[13]. The stress referred to in this research is cancer and cancer-related difficulties, and the BRS is able to assess TYAs abilities to bounce back from this using a brief and direct scale.

We considered three outcomes. (1) The Patient Health Questionnaire (PHQ-9)[21] is a nine-item scale used to assess symptoms of depression and suicidal ideation. Participants answered on a scale from 0 (not at all) to 3 (nearly every day) to indicate how often each problem bothered them over the past two weeks. Scores were summed and higher scores indicated greater severity of depression symptoms. This scale was found to be valid and reliable in a large sample of primary care patients[22]. (2) The Generalised Anxiety Disorder Assessment (GAD-7)[23] is a seven-item scale used to assess the presence and severity of anxiety symptoms. Participants answered on a scale from 0 (not at all) to 3 (nearly every day) to indicate how often each problem bothered them over the past two weeks. Scores were summed and higher scores indicated greater severity of anxiety symptoms. This scale was found to be reliable amongst cancer patients[24]. (3) Quality of Life was assessed using a single question designed by the TYA cancer clinic at Guy's Hospital which asked participants 'How would you rate your Quality of Life today?' from 0 (really bad) to 100 (really good).

We considered age, gender, and ethnicity as confounders due to their potential influence on both resilience and psychosocial outcomes. Age was measured at T_1 and collected by IMPARTS[18]. Gender (male or female) and ethnicity was extracted from electronic patient records. Ethnicity was categorised based on the five ethnic groups defined by the Office for National Statistics[25] (White, Mixed/Multiple Ethnic Groups, Asian/Asian British, Black/African/Caribbean/Black British, Other Ethnic Group) to aid with analysis as more specific categories would have resulted in small numbers in each group.

To describe the sample, we collected information about diagnoses and treatment type from electronic patient records. Discussions were held with clinicians from the TYA Cancer Service at Guy's Hospital to categorise diagnoses into clinically-similar groups so that future analyses can draw meaningful conclusions about the association between diagnosis and outcomes. For example, rather than categorising haemato-oncology into one group, Hodgkin's Lymphoma, which is usually treated with chemotherapy and has the possibility of complete remission post-treatment, was placed in a separate subgroup to Myeloproliferative Neoplasms (MPNs) where treatment is usually minimal but the condition itself can be lifelong.

Statistical analyses

Descriptive analyses were used to summarise participant demographics, clinical data (age at diagnosis, diagnosis, treatment type and length), and psychosocial outcome measures.

We then conducted two sets of regression models. First, we used separate multivariable linear regression models to analyse associations between resilience (BRS) measured at T_1 with depression (PHQ-9), anxiety (GAD-7) and quality of life at T_2. Second, we used separate multivariable linear regression models to assess how changes in resilience (from T_1 to T_2) were associated with depression, anxiety, and quality of life (measured at T_2).

Each model was adjusted for age, gender, ethnicity, and the T_1 measure of the outcome. Models analysing change in resilience over time were also adjusted for BRS scores at T_1. Due to non-normality and heteroscedasticity of residuals (see supplement B), regression coefficients and confidence intervals were estimated using bootstrapping (with 1000 bootstrap samples). We report the β coefficient for resilience (with bias-corrected bootstrap 95% confidence intervals) and model R^2. Analyses were carried out on IBM SPSS Statistics version 26.0.

Results

The analytical sample contained 63 TYAs, after excluding 298 TYAs who had not completed the outcome measures within 4 weeks of their treatment start date (T_1) and again between 9 and 15 months later (T_2). See Supplement A for further comparison of the excluded participants and the analytical sample. There were no major differences between included and excluded participants. The 63 TYAs completed psychosocial outcome measures between August 2013 and February 2020. Therefore, all data were collected prior to COVID becoming widespread and the impact that had on the NHS and wider society.

Presented in Table 1, most TYAs were male (59%) and of White ethnicity (67%). The second largest ethnic group was Asian/Asian British (14%) followed by Black/African/Caribbean/Black British (10%). The mean age at T_1 was 21.5 (Standard Deviation (SD) = 2.1) and at diagnosis was 21.3 (SD = 2.2). Average length of treatment was

7.2 months (SD = 11.1) after obtaining treatment start and end dates from electronic patient records.

Haemato-oncology was the largest diagnostic group (38.1%); however, once split into treatment subgroups, genitourinary was the largest group (19.0%) followed by neuroendocrine tumours (14.3%) and neuro/brain (11.1%). Surgery was the most commonly-reported single treatment type (30.2%), followed by chemotherapy (14.3%), then chemotherapy and radiotherapy combined (12.7%) and surgery and nuclear medicine combined (12.7%). This distribution of treatment types was expected given the types of diagnoses included in this sample.

Associations of resilience with psychosocial outcomes

On average at T_2, participants reported higher levels of resilience, fewer symptoms of anxiety and depression, and higher quality of life reported compared to T_1 (Table 2). Shown in Table 3, higher resilience at T_1 was associated with small increase in symptoms of anxiety (β = 1.68; Ba 95% confidence interval [-0.28, 3.19]), depression (β = 1.24; [-0.85, 2.90]) and subjective quality of life (β = 5.76; [-0.88, 15.60]) at T_2. For all three outcomes we found evidence of positive associations, but the 95% confidence intervals crossed zero.

An increase in resilience from T_1 to T_2 was associated with small to moderate decreases in anxiety (β = -3.16; [-5.22, -1.47]) and depression symptoms (β = -2.36, [-4.41, -0.58]) and a small to moderate increase in quality of life (β = 9.82, [-0.24, 21.13]), with the latter result not reaching statistical significance.

Discussion

This study aimed to explore the association between resilience and psychosocial outcomes in TYAs with cancer. We found higher levels of baseline resilience to be associated with increased symptoms of depression and anxiety and improved quality of life in TYAs 9 to 15 months later. Conversely, increases in resilience during cancer treatment were associated with reduced symptoms of depression and anxiety, and an improved quality of life.

We found support for our second hypothesis that increases in resilience over time would be associated with improved depression, anxiety, and quality of life. The BRS refers to

resilience as a stable concept[13]; however, resilience can be seen as something that is developed or modified over time and can be influenced by external resources such as social support and internal resources such a self-belief[26]. Further research has found that TYAs can gain meaning and greater appreciation for life after receiving a diagnosis of cancer which contributed to greater levels of resilience[27] and therefore supports the idea that resilience is a dynamic construct. This was found in the present study as increases in resilience over time were associated with better psychosocial outcomes.

On the other hand, we did not find support for our first hypothesis, that higher resilience at T_1 would be associated with reduced depression and anxiety at T_2. It is possible that at the start of the cancer journey, TYAs might feel that they can 'bounce back' and are somewhat resilient, but after 9 to 15 months of treatment they realise they are not as resilient as initially thought, and their way of coping might not be enough when they are faced with something like cancer. A systematic review exploring resilience and post-traumatic growth in TYAs with cancer found that TYAs felt like their resilience diminished during periods where they were faced with extreme anxiety or uncertainty[4]. This potential disconfirmation of a belief about themselves could contribute to the increase in reported symptoms of anxiety and depression at T_2. It therefore, could be important to consider additional psychosocial screening or monitoring of TYAs who initially present with high levels of resilience as they could be at risk of poorer psychosocial outcomes 9 to 15 months later.

Other potential contributing factors are the impact of treatment type or diagnosis on psychosocial outcomes. These factors were not included in the analysis due to the wide variation of diagnoses and treatment types leading to small sample sizes within each group. Previous research has found that gynaecological cancer was associated with higher levels of distress[28] and TYAs with leukaemia were more likely to report poor quality of life compared to those with lymphoma and solid tumours[29]. TYAs receiving chemotherapy or radiotherapy have also reported greater distress[6] compared with other types of treatment. Therefore, treatment type and diagnosis may influence psychosocial outcomes and further research should explore whether factors explain associations between resilience and psychosocial outcomes.

Our findings therefore suggest that interventions to maintain or even increase resilience over time could be important for TYAs so it is crucial for future research to explore ways in which resilience might be enhanced. This in turn may contribute to improved psychosocial outcomes. Promoting Resilience in Stress Management (PRISM)[15] is a brief 1:1 skills-based intervention which aims to improve psychosocial outcomes through goal setting, cognitive reframing and stress management. The Resilience Enhancement for Adolescents and Young Adults with Cancer and Healthcare Providers (REACH) is another intervention that identifies and fosters protective factors and highlights risk factors that require additional support[16]. Both interventions had high levels of satisfaction and PRISM was associated with improved resilience and cancer-related quality of life, and reduced distress[16,30] which links closely to the findings of the present study. Interventions such as PRISM and REACH therefore should be developed and evaluated with the aim to increase resilience in cancer treatment to improve psychosocial outcomes.

Limitations

Due to the small sample size, there was an increased chance of a type II error occurring. It will be important to replicate these findings with larger samples and in other centres to see whether our results are generalisable. We were unable to adjust for diagnoses and treatment type. All measures included in this study were self-report and the measure for quality of life contained a single question so may lack construct validity and replicability.

We were unable to account for non-health-related factors that could influence resilience, such as getting a first job or going to university. Research has found that, compared to adults, TYAs express greater concerns around work or education, finances, and fears around intimacy or sexuality due to disruptions of key developmental and transitional stages[31,32]. Stressors like this could therefore influence resilience and could contribute to the findings in this study.

Our analysis was also limited by looking at only two timepoints. Past research into trajectories of distress over time for TYAs with cancer found that symptoms of distress fluctuated over time[33]. In our study, despite baseline resilience being associated with symptoms of depression and anxiety at T_2, it was also associated with an increased quality

of life at T_2. Therefore, TYAs could experience increased anxiety or depression around a year after diagnosis (and probably treatment) while also experiencing a better quality of life. One study found that baseline distress was not associated with cancer-related quality of life in TYAs three to six months later meaning it is possible that these constructs are independent of each other[30].

Conclusion

This study found that increases in resilience during cancer treatment were associated with reduced symptoms of depression and anxiety and improved quality of life in TYAs with cancer. Future work should explore the contribution of factors such as diagnosis and treatment type and develop interventions that enhance resilience in TYA cancer populations.

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Table 1. Participant demographics and clinical data (n = 63)

	Frequency (Valid Percentage)				
	N avail.	Mean	SD	Min	Max
Gender					
Male			37 (58.7)		
Female			26 (41.3)		
Ethnic Origin					
White			42 (66.7)		
Mixed/Multiple Ethnic Groups			1 (1.6)		
Asian/Asian British			9 (14.3)		
Black/African/Caribbean/Black British			6 (9.5)		
Other Ethnic Group			5 (7.9)		
Age at T_1	63	21.5	2.1	17	24
Age at diagnosis	62	21.3	2.2	16	24
Missing	1				
Treatment Length (Months)	44	7.2	11.1	0	52
Treatment Outcomes					
Ongoing Treatment	14				
Died	2				
Missing	3				
Diagnostic Group					
Haemato-oncology:					
Hodgkin's			9 (14.3)		
Non-Hodgkin's			7 (11.1)		
MPN			2 (3.2)		
Cutaneous lymphoma			5 (7.9)		
Head and Neck			4 (6.3)		
Neuro/brain			7 (11.1)		
Gynaecological			2 (3.2)		
Skin			3(4.8)		
Genitourinary			12 (19.0)		
Neuroendocrine Tumour			9 (14.3)		
Other			3 (4.8)		
Treatment Type					
Surveillance			1 (1.6)		
Chemotherapy Only			9 (14.3)		
Chemotherapy and Radiotherapy			8 (12.7)		
Chemotherapy and Surgery			6 (9.5)		
Chemotherapy and BMT			1 (1.6)		
Radiotherapy Only			3 (4.8)		
Radiotherapy and Phototherapy			1 (1.6)		
Radiotherapy and Surgery			3 (4.8)		
Surgery Only			19 (30.2)		
Surgery and Nuclear Medicine			8 (12.7)		
Phototherapy Only			2 (3.2)		
Other			2 (3.2)		

(MPN= Myeloproliferative Neoplasms, BMT= Bone Marrow Transplant)

Table 2. Psychosocial Outcomes (n = 63)

Outcomes	T_1 Mean (SD) (range)	T_2 Mean (SD) (range)
BRS	3.6 (0.7) (1.3 – 4.8)	3.6 (0.8) (1.7 – 5.0)
GAD-7	5.0 (5.4) (0 – 21)	4.2 (5.4) (0 – 19)
PHQ-9	6.4 (6.1) (0 – 23)	5.5 (6.0) (0 – 23)
QoL	75.0 (19.1) (20 – 100)	78.1 (21.9) (8 – 100)

Table 3. Regression analyses showing the association between resilience, symptoms of anxiety and depression, and quality of life

Model			R^2	β	Ba 95% CI[†]	
				Resilience	Lower	Upper
1	T1 Resilience	GAD7	.35	.79	-1.41	2.82
2		GAD7 adjusted*	.55	1.68	-0.28	3.19
3	Change in Resilience	GAD7	.53	-3.73	-5.56	-2.07
4		GAD7 adjusted*	.64	-3.16	-5.22	-1.47
5	T1 Resilience	PHQ9	.54	.98	-.72	2.28
6		PHQ9 adjusted*	.61	1.24	-.85	2.90
7	Change in Resilience	PHQ9	.59	-2.27	-3.97	-.60
8		PHQ9 adjusted*	.65	-2.36	-4.41	-.58
9	T1 Resilience	QoL	.34	7.24	-.97	16.62
10		QoL adjusted*	.42	5.76	-.88	15.60
11	Change in Resilience	QoL	.39	7.54	-.93	15.11
12		QoL adjusted*	.48	9.82	-.24	21.13

*Adjusted for age, gender, ethnicity and T_1 outcome assessments.
[†] Bias-corrected bootstrap 95% confidence intervals.

Supplement A

Measures

IMPARTS collected a number of other psychosocial outcome measures that were not used in the main analysis for this study. They are reported in the descriptive statistics below and the measures were:

Patient-Reported Outcome Measurement Information System (PROMIS) Anger and Irritability (Short-form): This eight-item measure is used to assess angry mood, negative social cognitions and efforts to control anger. Higher scores indicate higher levels of anger/irritability symptoms.

Brief Illness Perception Questionnaire (BIPQ): This measure has eight items and is used to indicate an individual's cognitive and emotional perception of their illness. Higher scores show that the illness is seen as a greater threat.

Cognitive Function Screen: This six-item measure assesses cognitive functioning with higher scores reflecting greater satisfaction with cognitive abilities.

Distress Thermometer: This is a one-item measure that asks participants to rate on a scale from 0 to 10 how much they have been worried or upset about things over the past week. Higher scores indicate higher levels of distress.

Diagnostic Groups and Treatment Type

To ensure that information was non-identifiable, 'other' groups were created for both diagnosis and treatment type. The 'other' diagnostic group contains Langerhans Cell Histiocytosis, Myelodysplastic Syndromes, gastrointestinal cancer, lung cancer, unknown primary, multiple primary and Von Hippel-Lindau Syndrome. The 'other' treatment type group contains bone marrow transplant, aspirin, and hormonal treatments.

Descriptive Statistics

The analytical sample contained 63 TYAs after excluding 298 TYAs who had not completed the outcome measures within 4 weeks of their treatment start date (T_1) and again between 9 and 15 months later (T_2). The data in Table 1 shows descriptive statistics for the analytical sample, the excluded 298 TYAs and the whole group of 361 TYAs which contains both the analytical and excluded group.

In all groups there were more male TYAs however there was a slightly larger proportion of males in the analytical sample (66.7%) compared to the excluded group (50.7%) and whole group (52.1%). Across all group the majority of TYAs were White however, in the analytical sample there was a higher proportion of Asian/Asian British TYAs (14.3%) and fewer Black/African/Caribbean/Black British TYAs (9.5%) in comparison to the excluded group (7.4%, 15.8%) and the whole group (8.6%, 14.7%).

Age at diagnosis was similar across all groups (21.3 analytical sample, 20.4 excluded group, 20.6 whole group) and treatment length was slightly higher in the analytical sample (7.2 months) compared to the excluded group (6.0 months) and the whole group (5.8 months).

Haemato-oncology was the largest diagnostic group (38% analytical sample, 34% excluded group, 34% whole group) across all groups with neuro/brain being the next largest for the excluded group (20.8%) and the whole group (19.1%). Genitourinary was second largest for the analytical sample (19.0%) with neuroendocrine tumours third (14.3%) and then followed by brain/neuro (11.1%). It is possible that Myeloproliferative Neoplasms (MPN) and brain/neuro are underrepresented in the analytical sample, and this could be related to the frequency of follow up. TYAs with MPN are under lifelong treatment and TYAs with brain/neuro cancer are often under lifelong surveillance but not treatment meaning their visits to the TYA cancer clinic might be less frequent.

For the analytical sample descriptive statistics were reported for all psychosocial outcome measures collected by IMPARTS. On average, at T_2 there were higher levels of resilience, lower threat of illness, less satisfaction with cognitive functioning, fewer symptoms of anxiety and depression, less anger and distress, and a higher quality of life were reported compared to T_1.

Table 1. Participant demographics and clinical data

	Analytical Sample					Excluded Group					Whole Group				
	Frequency (Valid Percentage)					Frequency (Valid Percentage)					Frequency (Valid Percentage)				
	N	Mean	SD	Min	Max	N	Mean	SD	Min	Max	N	Mean	SD	Min	Max
Gender															
Male			37 (58.7)					151 (50.7)					188 (52.1)		
Female			26 (41.3)					147 (49.3)					173 (47.9)		
Ethnic Origin															
White			42 (66.7)					198 (69.5)					239 (69.0)		
Mixed/Multiple Ethnic Groups			1 (1.6)					16 (5.6)					17 (4.9)		
Asian/Asian British			9 (14.3)					21 (7.4)					30 (8.6)		
Black/African/Caribbean/Black British			6 (9.5)					45 (15.8)					51 (14.7)		
Other Ethnic Group			5 (7.9)					5 (1.8)					10 (2.9)		
Missing			-					13					13		
Age at T_1	63	21.5	2.1	17	24	298	21.5	2.5	15	27	361	21.5	2.4	15	27
Age at diagnosis	62	21.3	2.2	16	24	294	20.4	3.2	1	25	356	20.6	3.1	1	25
Missing	1					4					5				
Treatment Length (Months)	44	7.2	11.1	0	52	145	6.0	11.5	0	62	189	5.8	11.0	0	62
Treatment Outcomes															
Ongoing Treatment	14					91					105				
Died	2					13					15				
Missing	3					49					52				
Diagnostic Group															
Haemato-oncology:															
Hodgkin's			9 (14.3)					37 (12.4)					46 (12.7)		
Non-Hodgkin's			7 (11.1)					12 (4.1)					19 (5.2)		
MPN			2 (3.2)					28 (9.4)					30 (8.3)		
Cutaneous lymphoma			5 (7.9)					18 (6.0)					23 (6.4)		
ALL			-					3 (1.0)					3 (0.8)		
Head and Neck			4 (6.3)					6 (2.0)					10 (2.8)		
Neuro/brain			7 (11.1)					62 (20.8)					69 (19.1)		
Breast			-					3 (1.0)					3 (0.8)		
Gynaecological			2 (3.2)					11 (3.7)					13 (3.6)		

Sarcoma	-	10 (3.4)	10 (2.8)
Skin	3 (4.8)	12 (4.0)	15 (4.2)
Genitourinary	12 (19.0)	52 (17.4)	64 (17.7)
Neuroendocrine Tumour	9 (14.3)	32 (10.7)	41 (11.4)
Other	3 (4.8)	13 (4.4)	15 (4.2)
Treatment Type			
Surveillance	1 (1.6)	20 (6.8)	21 (5.9)
Chemotherapy Only	9 (14.3)	48 (16.4)	57 (16.1)
Chemotherapy and Radiotherapy	8 (12.7)	22 (7.5)	30 (8.5)
Chemotherapy and Surgery	6 (9.5)	42 (14.4)	48 (13.5)
Chemotherapy and BMT	1 (1.6)	4 (1.4)	5 (1.4)
Chemotherapy and Other	-	2 (0.7)	2 (0.6)
Radiotherapy Only	3 (4.8)	5 (1.7)	8 (2.3)
Radiotherapy and Phototherapy	1 (1.6)	1 (0.3)	2 (0.6)
Radiotherapy and Surgery	3 (4.8)	7 (2.4)	10 (2.8)
Surgery Only	19 (30.2)	94 (32.2)	113 (31.8)
Surgery and Nuclear Medicine	8 (12.7)	18 (6.2)	26 (7.3)
Immunotherapy Only	-	4 (1.4)	4 (1.1)
Phototherapy Only	2 (3.2)	7 (2.4)	9 (2.5)
Other	2 (3.2)	11 (3.7)	13 (3.6)
Combination of 3 or more treatments	-	7 (2.3)	7 (1.7)
Missing	-	6	6

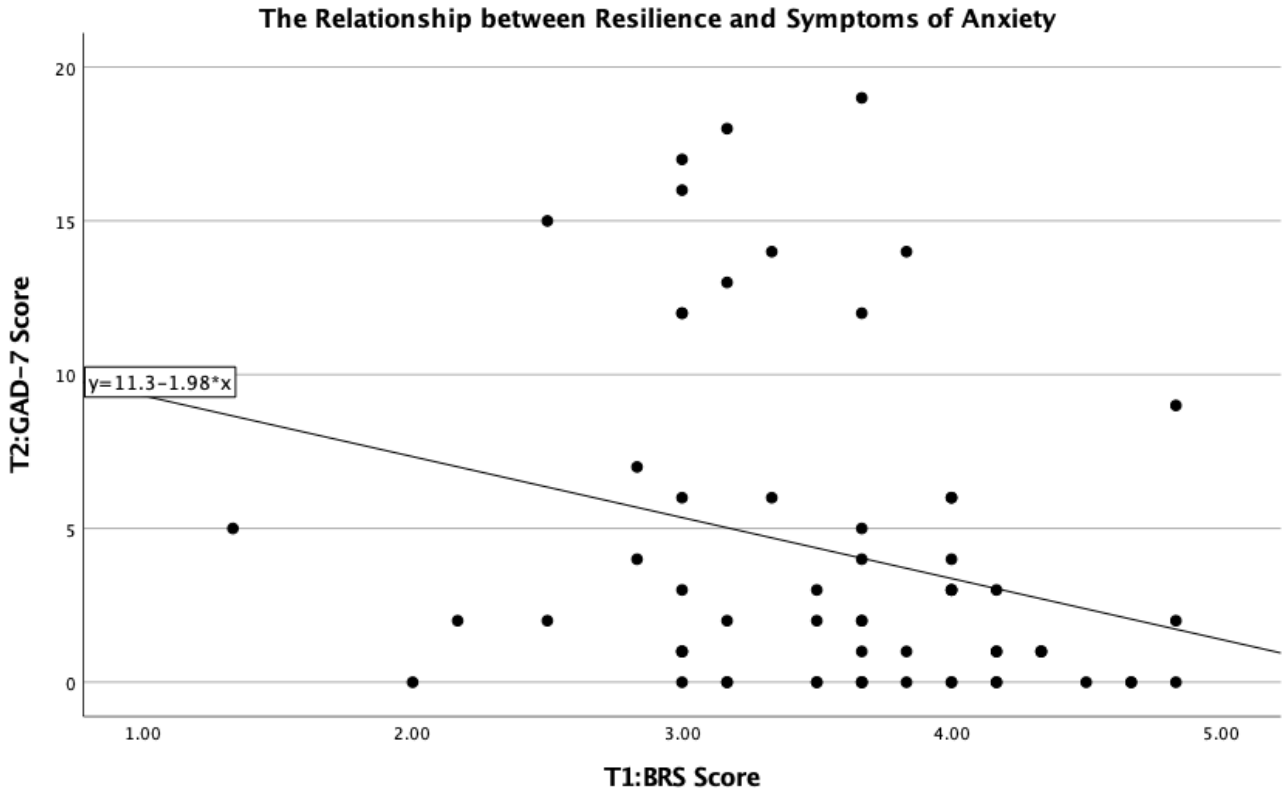
(MPN= Myeloproliferative Neoplasms, ALL= Acute Lymphoblastic Leukaemia, BMT=Bone Marrow Transplant)

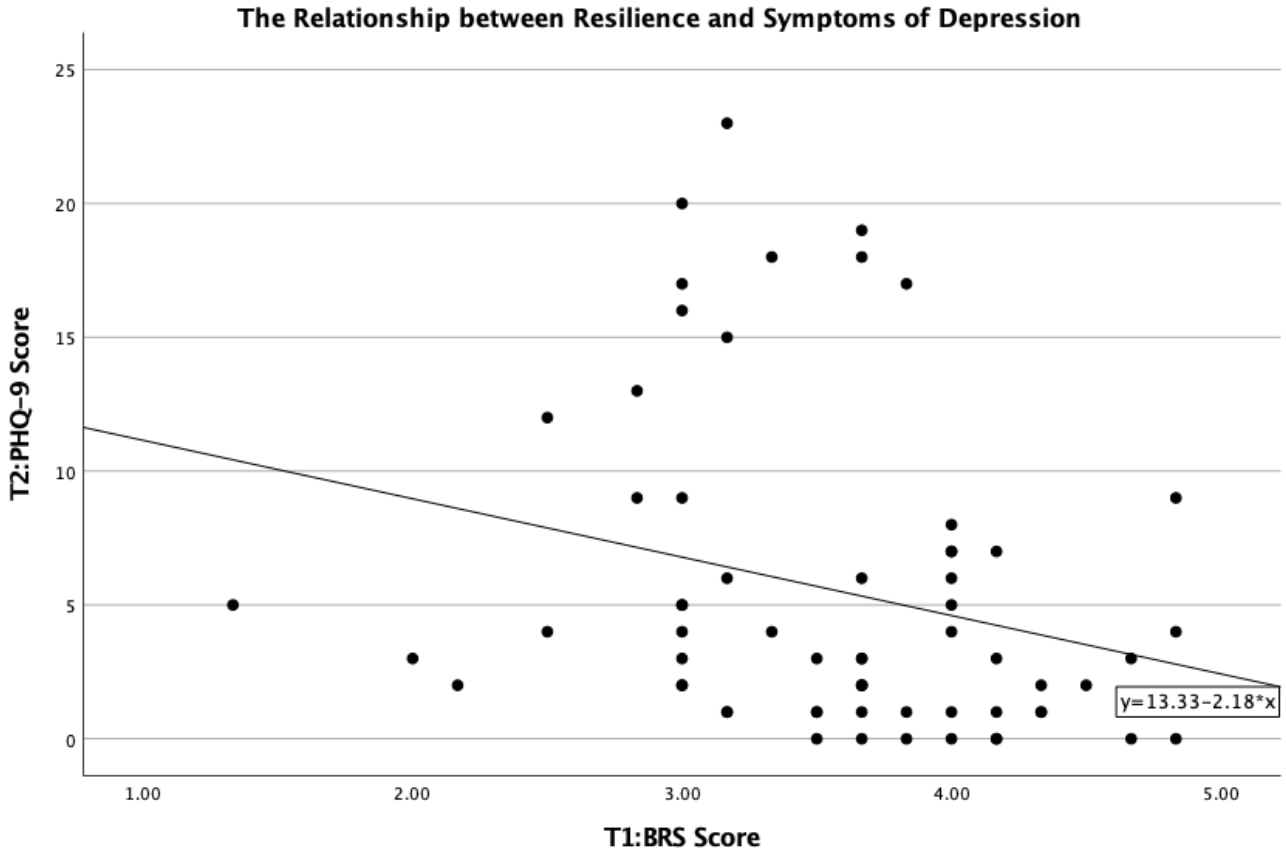
Table 2. Psychosocial Outcomes

Outcomes	T_1 Mean (SD) (range)	T_2 Mean (SD) (range)
BRS	3.6 (0.7) (1.3 – 4.8)	3.6 (0.8) (1.7 – 5.0)
GAD-7	5.0 (5.4) (0 – 21)	4.2 (5.4) (0 – 19)
PHQ-9	6.4 (6.1) (0 – 23)	5.5 (6.0) (0 – 23)
QoL	75.0 (19.1) (20 – 100)	78.1 (21.9) (8 – 100)
Brief Illness Perception	33.8 (13.5) (3 - 68)	26.1 (17.0) (0 - 64)
Anger/Irritability	8.4 (8.0) (0 - 32)	7.0 (7.9) (0 - 27)
Cognitive Functioning	23.2 (5.8) (6 - 30)	22.0 (5.9) (8 - 30)
Missing	1	-
Distress Thermometer	3.7 (2.6) (0 – 9)	2.2 (2.6) (0 – 9)
Missing	17	2

Supplement B

1. The relationship between the independent and dependent variables was linear:





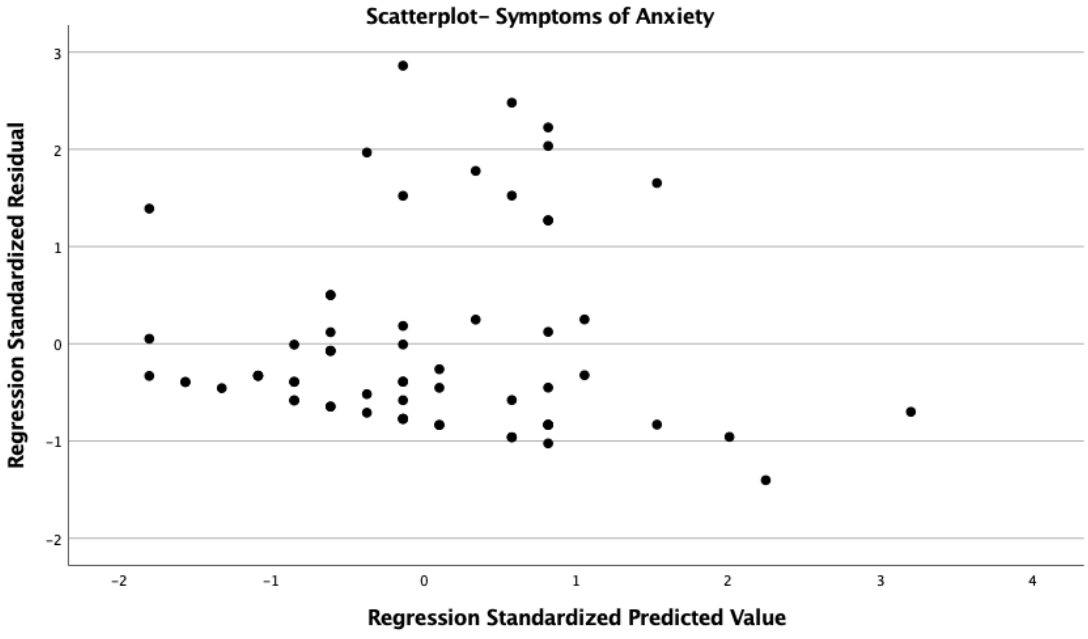
2. There is no multicollinearity of the data as VIF values were 1.0

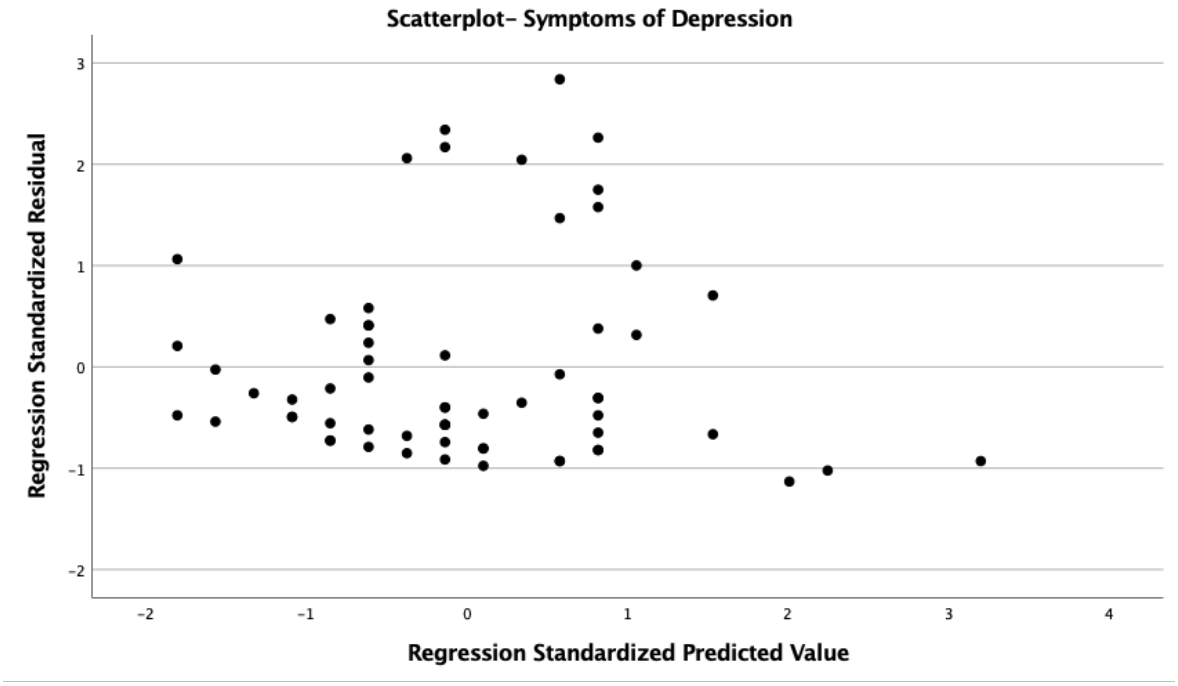
3. The values of the residuals are independent as Durbin Watson values are between 1.5 and 2.5

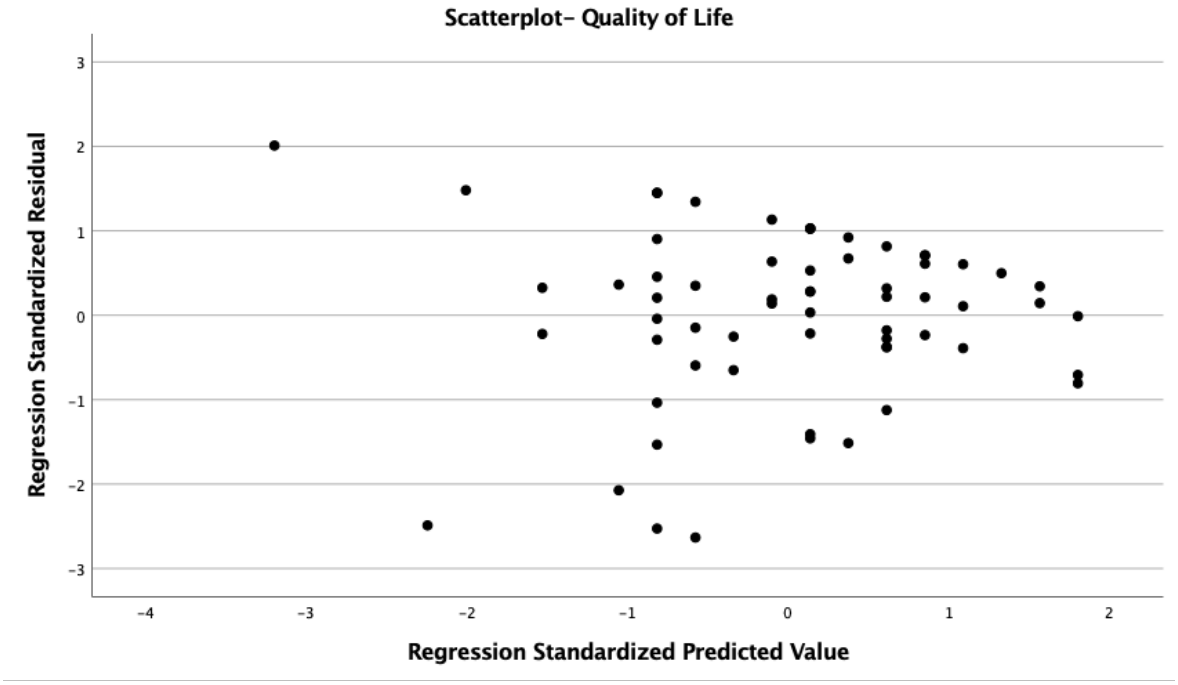
	Durbin-Watson
T2:GAD7	1.67
T2:PHQ9	1.75
T2:Quality of Life	1.71

(Predictor T1:BRS)

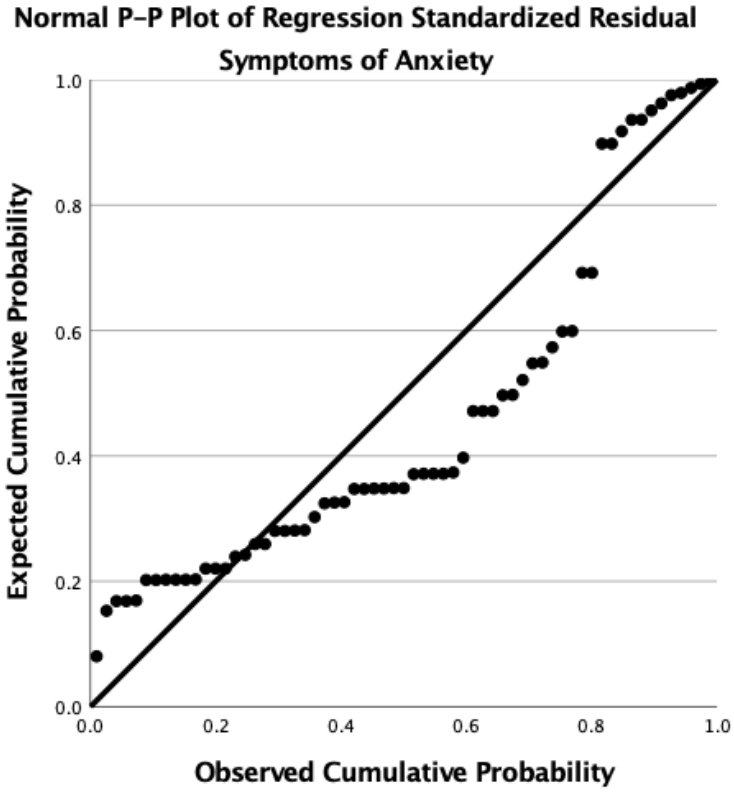
4. There variance of residuals was not constant due to heteroscedasticity:

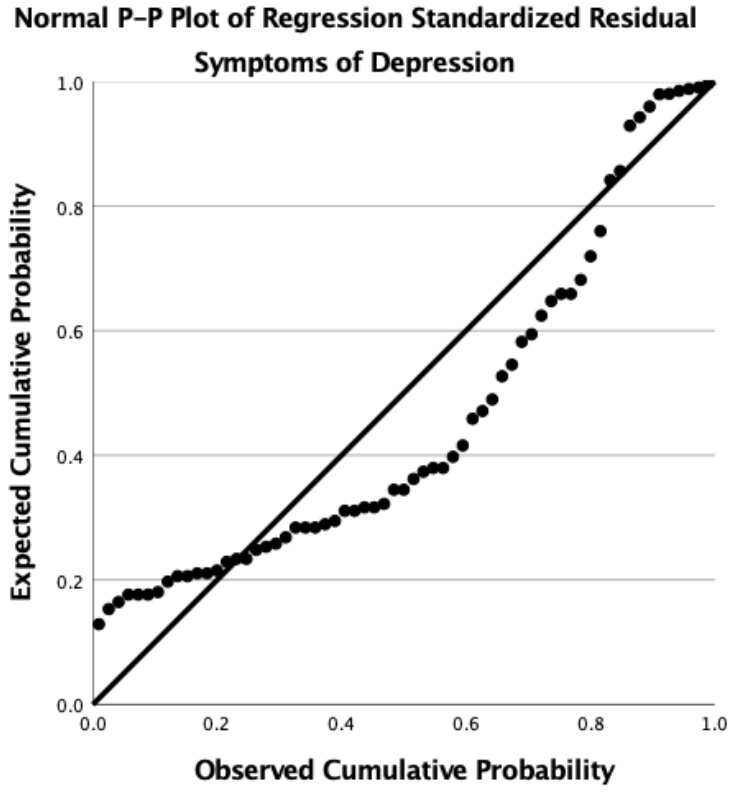


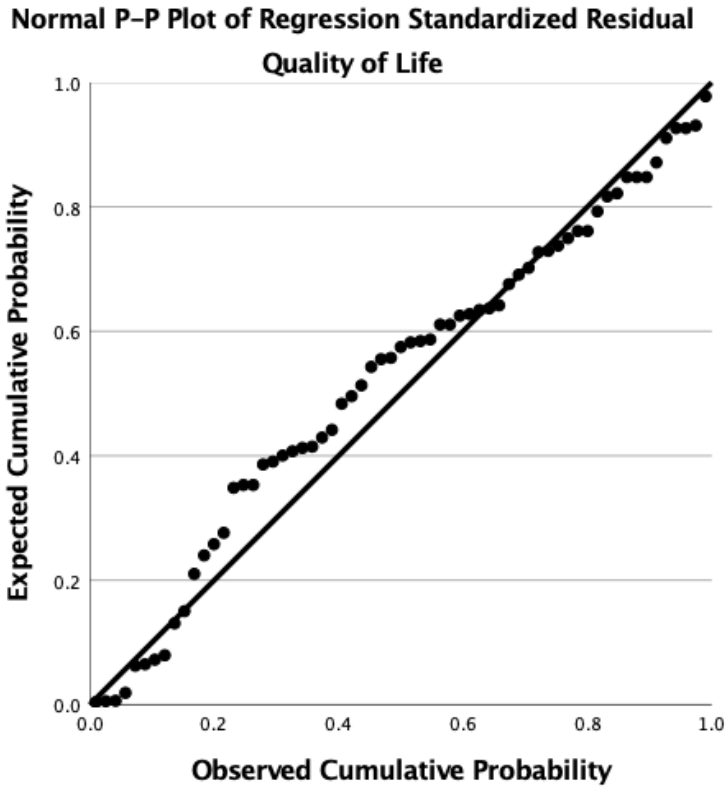




5. The values of the residuals were not normally distributed:


Normal P-P Plot of Regression Standardized Residual
Symptoms of Anxiety
Expected Cumulative Probability
Observed Cumulative Probability
0.0
0.2
0.4
0.6
0.8
1.0


Normal P-P Plot of Regression Standardized Residual
Symptoms of Depression
Expected Cumulative Probability
Observed Cumulative Probability
0.0
0.2
0.4
0.6
0.8
1.0



6. There are no influential cases biasing the model as Cook's distance values were below 1

Chapter 2- Part 2

Empirical Project

Trajectories of Resilience and Anxiety in Teenage and Young Adult Cancer

Supervised by Dr Susie Henley, Dr Ewan Carr, & Dr Clare Jacobson

Table of Contents

Abstract

Purpose

There is limited research into the psychological impact of cancer on teenagers and young adults (TYAs) and no research into the differences by diagnostic group. This study examined longitudinal associations between resilience and anxiety in TYA cancer and tested whether these associations differed by diagnostic group (genitourinary, haematological, and brain/neurological cancer).

Methods

Data were collected between 2013 to 2021 from teenagers and young adults (aged 16-24) who attended the TYA Cancer Service at Guy's Hospital, London. Latent growth curve models were used to model individual trajectories of resilience and anxiety in the 15 months following a cancer diagnosis. Parallel process growth curve models were used to estimate covariances between anxiety and resilience trajectories. Multiple groups models were used to test for differences between diagnostic groups in two specific associations: (1) between initial resilience (0 months) and subsequent change in anxiety; (2) between the change in resilience and change in anxiety.

Results

Higher resilience at diagnosis was associated with larger increases in anxiety over the subsequent 15 months (Covariance (Cov) = 0.23, $p = 0.001$). By contrast, increases in resilience over 15 months were associated with greater decreases in anxiety over the same period (Cov = -0.05, $p < 0.001$). We found statistically significant differences between the three diagnostic groups in associations between initial resilience and subsequent changes in anxiety over 15 months (Wald Test (W_T) = 8.71, $p = 0.013$), but there was no evidence of differences for associations between changes in anxiety and changes in resilience (W_T = 1.84, $p = 0.397$).

Discussion

Higher resilience at diagnosis was associated with larger increases in anxiety in the subsequent 15 months, whereas increases in resilience in this period were associated with greater decreases in anxiety. We found preliminary evidence that these associations differed by cancer diagnosis. Future research should replicate this work in larger samples and consider differences for other cancer types and diagnoses.

Introduction

Teenagers and Young Adults (TYAs) with cancer face specific challenges due to disruptions to key developmental and transitional stages[1,2]. TYAs, typically defined as 16-24 in the UK[3], have unique psychosocial needs as they try to navigate education, work, and the transition towards greater independence while battling with the distress caused by cancer and its treatment[4,5]. This distress can place significant strain on relationships and family life, and TYAs are faced with reduced autonomy as a result of their diagnosis[5,6]. The psychological and physical difficulties can lead to conflicts of identity and impact on TYAs ability to cope[4,7]. TYAs have unique experiences compared to both children and older populations with cancer and often have unmet needs as a result[8-10]. It is crucial for research to focus on this age group separately from both paediatric and adult populations, in order to address the particular needs of these young people[9].

TYAs with cancer are at significantly increased risk of poor psychosocial outcomes[9] including anxiety and fear of cancer recurrence[8,11]. Uncertainty surrounding their cancer diagnosis and treatment can cause worry and depression[6] with one in four TYAs reporting psychological distress[8]. Research into symptom-burden in TYA cancer found that anxiety and fatigue were the most prevalent issues with 44% of TYAs reporting moderate to severe levels of anxiety[11]. Fear of cancer recurrence has been reported in the majority of TYAs and is more prevalent in this group compared to older cohorts with cancer[8]. It is therefore important for research into TYAs with cancer to focus on the psychosocial challenges associated with the illness such as anxiety.

The use of a positive psychological approach is key for TYAs to augment strengths and to build the resources needed to cope with cancer[1,5]. Resilience plays a large part in this approach and is defined as the ability to develop resources to manage and bounce back from substantial stressors, such as illness, that pose a significant threat to one's life or functioning[5,12]. Interventions that increase resilience have been shown to improve QoL, hope, and distress[13,14], and increase health-promoting behaviours[15].

The research in Part 1 of this empirical project explored the associations between initial resilience (around the start of treatment) and changes in resilience (over 9-15 months post treatment start date) with symptoms of anxiety and depression, and self-rated quality of life. We found that higher levels of baseline resilience were associated with increased symptoms of depression and anxiety and improved quality of life in TYAs 9-15 months later, but these findings did not reach statistical significance. Conversely, increases in resilience during cancer treatment were associated with reduced symptoms of depression and anxiety and improved quality of life. These associations were statistically significant for depression and anxiety, but not for quality of life. In the present study we further explored the association of resilience and anxiety by modelling trajectories over time to allow for a larger sample size to be included. It was hoped that increasing the sample size would reduce the likelihood of a type II error occurring and would allow us to explore whether the findings in Part 1 were replicable.

Different cancer diagnoses and their associated treatments can have different impacts on psychosocial outcomes. Past studies among TYAs have found higher levels of distress associated with gynaecological cancers[16], digestive system, breast, or head and neck cancers[17], or those receiving chemotherapy or radiotherapy[17]. Anxiety is particularly prevalent prior to a bone marrow transplant, with depression being a common symptom at 6 months post-transplant[18]. Despite this evidence, however, research into the impact of cancer diagnoses and their associated treatments on psychosocial outcomes among teenagers and young people is sparse. Further research in this area is needed in order to allocate and tailor psychosocial interventions effectively[4,7]. The current study therefore also examined whether the association between resilience and anxiety differed between cancer types.

Aims and Hypotheses

Previous research has demonstrated some evidence for the protective effect of resilience on anxiety. However, past research is limited due to the lack of longitudinal studies or studies examining this association by different cancer diagnoses. Therefore, this study aimed to explore associations between resilience and anxiety in the 15 months after an initial

diagnosis. Based on repeated assessments of TYAs at the TYA Cancer Service at Guy's Hospital, we considered how changes in resilience were related to changes in anxiety. We further explored how these associations varied by diagnostic group (genitourinary cancer, haematological cancer comprised of Hodgkin's and Non-Hodgkin's Lymphoma, and brain/neurological cancer). We hypothesised that:

Hypothesis 1:	Higher resilience at diagnosis would be associated with smaller increases in anxiety over the following 15 months.
Hypothesis 2:	Increases in resilience in the 15 months after diagnosis would be associated with decreases in anxiety over the same period.
Hypothesis 3:	There would be differences in these associations between genitourinary, haematological, and brain/neurological cancer diagnoses. This exploratory hypothesis was non-directional as no previous research has addressed this question.

Methods

Sample

This study used data collected prospectively as part of 'Integrating Mental and Physical Healthcare: Research, Training, and Service' (IMPARTS)[19,20], an initiative that aims to integrate mental and physical healthcare into research, training, and clinical work. As part of this project, data was collected for 361 TYAs who attended the TYA Cancer Service at Guy's Hospital between 2013 and 2021. All TYAs were diagnosed between ages 16-24 and this is typically the UK age range for TYAs[10]. While this period overlapped with the COVID-19 pandemic (March 2020 to 2021), information from this period was collected for a single TYA. The TYA Service is an adjunct psychosocial support service offered to patients who are receiving cancer or brain tumour treatment at Guy's and St Thomas' Hospitals, King's

College Hospital, or partner local hospitals. During the follow-up period (2013-2021), the TYA service looked after approximately 601 TYAs with an average of 66 TYAs being referred each year. TYAs attended the TYA Cancer clinic approximately every three months and completed questionnaires on an iPad or smartphone during their appointment. Completion of the questionnaires was voluntary. These questionnaires collected information on psychosocial measures, demographic data, and clinical information. The IMPARTS project provides generic ethical approval for analysis of this pseudo-anonymised data (REC Ref: 18/SC/0039). TYAs were informed that their anonymised data might be used for research purposes and were made aware of their right to opt-out at any time. Electronic patient records were searched to extract gender, ethnicity, diagnosis, and treatment type.

Timepoints

This study included TYAs who had, as a minimum, completed at least one assessment in the 15 months following an initial diagnosis. We chose a 15-month follow-up period since TYAs were invited to attend the clinic every 3 months and clinicians suggested 15 months was a reasonable length of time to detect reliable changes in outcomes. The length of time TYAs are cared for by the TYA service varies based on age at diagnosis, treatment plan, and prognosis; however, the majority do stay for as long as they are able to (until age 25 or at least 2 years after they finish treatment). For analysis, we grouped individual assessments (taken on a specific day) into three-month bins to ensure an adequate sample size at each time point.

Measures

IMPARTS included a battery of questionnaires from which we selected the following outcomes in order to address our specific research question. We chose to focus on anxiety following discussions with clinicians who identified anxiety as the most commonly-reported psychological concern in TYA cancer populations. (1) The Generalised Anxiety Disorder Assessment (GAD-7[21]) was used to assess symptoms of anxiety. This seven-item scale asks participants to rate how often each problem bothered them over the past two weeks from 0 (not at all) to 3 (nearly every day). Higher total scores indicated greater severity of anxiety

symptoms with 5, 10, and 15 being cut-offs for mild, moderate, and severe symptoms of anxiety respectively. The GAD-7 has been identified as a reliable screening tool among cancer populations[22]. (2) The Brief Resilience Scale (BRS[23]) is a six-item scale used to assess participant's resilience. Participants rated the extent to which they agreed with each statement on a five-point scale from 'strongly disagree' to 'strongly agree'. Three items are positively worded, three are negatively worded, and the scale is scored by reverse coding the negative items before calculating the mean of all six items. Higher levels of resilience are indicated by higher total scores. The BRS was found to be a reliable scale across four samples of students and cardiac and chronic pain patients[24].

Information on diagnosis and treatment type was manually extracted by KH from electronic patient records. Clinicians from the TYA Cancer Service at Guy's Hospital helped categorise diagnoses into clinically-similar groups so that meaningful conclusions could be drawn about the association between diagnoses and outcomes. To explore whether associations between resilience and anxiety differed by cancer diagnosis we selected the largest three diagnostic groups: genitourinary cancers, haematological cancers (comprised of Hodgkin's and Non-Hodgkin's Lymphoma), and brain/neurological tumours. Hodgkin's and Non-Hodgkin's lymphoma were grouped together following discussions with clinicians where it was decided their similar treatments meant they could be categorised as a clinically-similar group. We chose these three groups for clinical and pragmatic reasons to test hypothesis 3 since they were clinically distinct in terms of typical presentation, treatment, and outcome, and were the largest groups in our sample.

Age at diagnosis, gender, and ethnicity were considered confounders in this research. Age at diagnosis was collected by IMPARTS while gender (male or female) and ethnicity were collected from electronic patient records. Ethnicity was categorised into White, Mixed/Multiple Ethnic Groups, Asian/Asian British, Black/African/Caribbean/Black British, and Other Ethnic Group as suggested by the Office for National Statistics[25].

Statistical Analysis

We conducted the analyses in five steps.

First, we described the demographic and clinical information, including diagnosis and treatment type, using appropriate summary statistics.

Second, we separately modelled individual trajectories in anxiety and resilience in the 15 months following diagnosis using latent growth curve models. Latent growth curves are latent variable models, estimated in a structural equation modelling framework, that model repeated outcome assessments in terms of an intercept and slope. We considered linear and quadratic trajectory models. For anxiety and resilience separately, we chose the final model based on model fit indices and substantive interpretability. The model fit indices used were the Chi-square test of model fit (for good fit *p* should be > 0.05), Root Mean Square Error of Approximation (RMSEA; values closer to 0 represent good fit but should be < 0.08), Comparative Fit Index (CFI; good fit is > 0.90), and Tucker–Lewis Index (TLI; good fit is > 0.90). These models were adjusted for age at diagnosis, gender, and ethnicity.

Third, we estimated the covariances between anxiety and resilience trajectories using a parallel process growth curve model. This model was adjusted for age at diagnosis, gender, and ethnicity.

Fourth, we considered separate quadratic trajectories of resilience and anxiety for each of the three diagnostic groups. These models were adjusted for age at diagnosis, gender, and ethnicity but, due to the small sample size within each diagnostic group, the 'Mixed/multiple' and 'Other' ethnic groups were combined.

Finally, we used multiple group latent growth curve models to test whether there were differences between diagnostic groups in two specific associations: (1) between initial resilience and subsequent change in anxiety; and (2) between the change in resilience and change in anxiety. These pathways were tested in turn using a Wald test by constraining the relevant path coefficients to be equal across groups (via "MODEL TEST" in Mplus). Due to the complexity of the model and the small sample size within each diagnostic group, we were unable to adjust the multiple-group models for confounders.

Missing data was accounted for by maximum likelihood. Models were estimated using Mplus version 8.7[26]; data were prepared using R version 4.2.2[27].

Results

From the 361 IMPARTS participants that attended the TYA cancer service, we excluded participants without any outcome assessments in the 15 months following their diagnosis (n=143), those missing information on confounders (n=3), and those missing information on GAD or BRS (n=16) (See Figure 1). The analytical sample therefore contained 199 participants (a total of 560 repeated assessments of GAD-7 and 562 of BRS). When testing for differences between diagnostic groups we further restricted the sample to 113 participants belonging to either the genitourinary (n=43), haematological (n=37) or brain/neurological (n=33) groups.

Descriptive statistics

Table 1 presents clinical and demographic characteristics of the analytical sample (n = 199) and excluded participants (n = 162). In the analytical sample, most TYAs were male (57%) and of White ethnicity (68%). The mean age at diagnosis was 21.2 (standard deviation (SD) = 2.2). The three largest diagnostic groups were haemato-oncology (30% for the group as a whole or 19% for Hodgkin's and Non-Hodgkin's only), genitourinary (22%), and brain/neurological (17%). Surgery was the most commonly-reported treatment type (32%) followed by surgery and chemotherapy combined (16%) and then chemotherapy only (15%).

Excluded participants tended to be similar to the analytical sample in terms of ethnicity (White ethnicity = 69%) however, were majority female (54%), and the mean age at diagnosis was slightly younger at 19.8 (SD = 3.7). In the excluded group, the largest diagnostic groups were haemato-oncology (38% as a whole or 19% for Hodgkin's and Non-Hodgkin's only), brain/neurological (22%), and genitourinary (13%) while the most common treatment was surgery only (32%) followed by chemotherapy only (17%).

Separate trajectories of anxiety and resilience over 15 months

We chose quadratic trajectory models on the basis of model fit and interpretability (see Figures 2 and 3). We found a positive relationship between initial levels of anxiety at diagnosis and increases in anxiety over the subsequent 15 months (intercept-slope

covariance (Cov_{IS}) = 3.16), but these associations did not reach statistical significance (p = 0.162). We did find evidence of a statistically significant positive covariance between initial resilience and subsequent changes in resilience over 15 months (Cov_{IS} = 0.08, p = 0.035). This indicates that TYAs reporting a higher level of resilience at diagnosis tended to experience greater growth in their resilience levels over the subsequent 15 months. For further details on the means and variances see Supplement A where the statistics are reported for the adjusted and unadjusted models at each stage of the analysis.

Figure 4 presents the sample and model estimated means from the separate trajectory models. For anxiety, the mean score at diagnosis was 5.0 (on a scale from 0 to 21) and scores tended to decline over the subsequent 15 months. For resilience, the initial mean score was 3.6 (range: 1-5) and scores tended to increase over the same period.

Associations between resilience and anxiety

Parallel process models were used to explore associations between resilience and anxiety (Figure 5). We tested two specific covariances. First, we found resilience at diagnosis to be positively associated with changes in anxiety over the subsequent 15 months (Cov_{SGIB} = 0.23; p = 0.001). This indicates that TYAs with higher initial levels of resilience tended to experience larger increases in anxiety over the follow-up period.

Secondly, we found changes in resilience in the 15 months following diagnosis to be negatively associated with changes in anxiety over the same period (Cov_{SBSG} = -0.05; p < 0.001). This indicates that TYAs who experienced larger increases in resilience since diagnosis tended to experience larger decreases in anxiety over this period, compared to TYAs with smaller increases in resilience.

Associations between resilience and anxiety by diagnostic group

Figure 6 presents the sample and estimated means for trajectories of anxiety and resilience separately for the genitourinary, haematological, and brain/neurological cancer groups.

Table 2 presents differences by diagnostic group in two specific pathways: (1) the association of initial resilience with change in anxiety; and (2) the association of change in resilience with change in anxiety. For (1), we found evidence of statistically significant differences between the three diagnostic groups when looking at associations of initial resilience with changes in anxiety (Wald Test for constraint of equality across diagnostic group (W_T) = 8.71, p = 0.013). Whereas initial resilience and changes in anxiety were positively associated in both the genitourinary and haematology groups, a negative association was observed in the brain/neurological group. Conversely, we found no evidence of a statistically significant difference between the three diagnostic groups for associations between the changes in resilience and the changes in anxiety (W_T = 1.84, p = 0.397).

Discussion

This is one of the first longitudinal studies to consider associations between resilience and anxiety in TYAs with cancer. We found that TYAs with higher initial levels of resilience tended to experience larger increases in anxiety over the follow-up period. TYAs whose resilience levels increased over the initial 15 months following diagnosis tended to experience greater decreases in anxiety over the same period. We explored whether this association varied between different types of cancer (genitourinary, haematological, and brain/neurological cancer) and found evidence of statistically-significant group differences in the associations between resilience at diagnosis and changes in anxiety over the subsequent 15 months.

These findings were not in line with hypothesis 1 as higher initial resilience was associated with larger increases in anxiety in the 15 months following diagnosis. We hypothesised that higher resilience at diagnosis would be associated with smaller increases in anxiety over time given previous research states that resilience enables individuals to adapt to threatening situations and thus alleviates anxiety[28]. However, the social-cognitive transition model of adjustment suggests that someone's assumptions and expectations about how they will cope with something like cancer, can either be confirmed or disconfirmed based on their experience[29]. TYAs who believe they are resilient at the start of their cancer journey

might in fact struggle to 'bounce back' following treatment and therefore, this could lead to an increase in anxiety as they feel less confident in their ability to cope with their diagnosis. Part 1 of this empirical project also found that higher levels of baseline resilience were associated with increased symptoms of anxiety. Given that the present study replicated this finding and reached statistical significance, this empirical project has demonstrated that higher resilience at cancer diagnosis/start of treatment might not be a good indicator of somebody's ability to cope with cancer.

We found support for our second hypothesis as increases in resilience over 15 months following diagnosis were associated with greater decreases in anxiety in the same period. This reflects the findings in Part 1 of this empirical project and was expected as an increase in resilience means TYAs are developing resources to cope with cancer[5,12] which can relieve symptoms of anxiety. The 'Promoting Resilience in Stress Management' intervention which aimed to target resilience resources such as stress management and cognitive reframing was found to improve psychosocial outcomes[10] including levels of worry over time[30]. This suggests that increases in resilience over time may alleviate symptoms of anxiety among TYAs.

Hypothesis 3 was non-directional due to the exploratory nature of this research. Consistent with hypothesis 3, we found a statistically-significant difference between the three diagnostic groups for the association between initial resilience at diagnosis and changes in anxiety over the subsequent 15 months. However, further research is needed to explore pairwise comparisons, for example comparing genitourinary cancer with haematological cancer or brain/neurological cancer with haematological cancer. The differences between the three groups are likely explained by the different treatments and prognoses associated with each diagnosis. For the haematological group, TYAs tend to have weekly chemotherapy for several months and are then followed up under surveillance[31] whereas the genitourinary group are more likely to have surgery only or surgery and chemotherapy combined[32]. Typically, within the 15 months following these diagnoses and treatments, patients in these two groups will be told they are in remission[31,32]. In the brain/neurological group many patients are put on surveillance (no active treatment, but the need to be on constant alert for a change in symptoms which could necessitate treatment) or are offered surgical intervention followed by surveillance[33]. Patients in this group are much more likely to be on

lifelong surveillance, with incomplete tumour clearance, compared to the other two groups[33].

We found no evidence for differences between the three diagnostic groups in the association between changes in resilience and changes in anxiety in the 15 months following diagnosis. Due to the small sample size within each diagnostic group, it is possible this study lacked power to be able to detect a true effect. Further work is therefore needed to replicate these findings in larger samples.

Previous research on trajectories of distress in TYA cancer has shown an overall decline in distress in the 12 months following initial diagnosis, but, within that, an increase in distress from 6 to 12 months[34]. The period post-6 months might reflect survivorship concerns including the late effects of cancer and fear of cancer returning[34,35]. Fear of cancer recurrence has also been associated with poor prognosis and adjuvant treatment[36]. While no research into TYA cancer has looked at the association of different cancer diagnoses on anxiety, research in adult cancer has found individuals with testicular and haematological cancer to have fewer symptoms of anxiety compared to brain cancer[37]. The symptoms associated with brain/neurological cancers can be particularly distressing if they affect breathing or the central nervous system, and the poorer prognosis was found to increase anxiety and depression[37]. It is therefore possible that research into different cancer types in TYAs with a larger sample size than the present study might discover similar findings.

Strengths and limitations

This study used a longitudinal, repeated measures design to explore the association between resilience and anxiety in TYA cancer. Data was collected as part of routine clinical practice meaning it was truly representative of TYA cancer populations and thus demonstrated ecological validity. We were able to include all participants with at least one outcome assessment in the 15 months following diagnosis and adjust for several potential confounders. This was the first study to explore whether the association between resilience and anxiety varied in different cancer types.

However, this study did have a number of limitations. The diagnostic groups were chosen pragmatically in order to maximise sample size, rather than on any clinical or theoretical criteria. The small sample size within each diagnostic group meant it was not possible to adjust for confounders in all models, nor possible to test any pairwise differences between the three groups. It is also possible that there were further confounders that were not adjusted for such as socioeconomic or immigration status, family support, prognosis, or staging which might have influenced the findings[35]. This was a prospective cohort study design using data collected in a single centre during a specific time period but completion of the questionnaires was voluntary and not all TYAs treated in the hospital opted in for the TYA service. Those TYAs who did opt in did not all complete the questionnaires and sometimes did not attend appointments within the initial three-month time period. It is also unknown whether TYAs with learning disabilities completed the questionnaires. Thus, the sample is relatively self-selective and this must be taken into account when considering how representative and generalisable the results are. These interesting preliminary findings should be followed up with a larger prospective study, focusing on one or two key cancer types in TYAs and collecting data at specific time points in order to reduce these sources of bias.

Conclusion

In a sample of 199 TYAs attending a cancer service in central London, we found that higher resilience at the point of diagnosis was associated with larger increases in anxiety in the 15 months following diagnosis whereas increases in resilience were associated with greater decreases in anxiety over the same period. We further found preliminary evidence that the association between resilience and anxiety differed by cancer type (haematological, genitourinary, and brain/neurological cancer) in our TYA sample.

Screening for resilience and anxiety in clinical practice allows clinicians to recognise those at risk for poorer mental health and tailor their psychosocial interventions accordingly. Psychosocial interventions to improve resilience are likely to be beneficial in reducing anxiety, and TYAs with different types of cancer may benefit from specific interventions at different points in their treatment pathway given the potential differences in trajectories.

Future research should explore these associations in larger samples and among other diagnostic groups to further clarify how psychosocial outcomes differ between types of cancer in TYAs, and therefore how the young people can best be supported.

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Figure 1. Flow chart showing sample size at each stage of the analysis

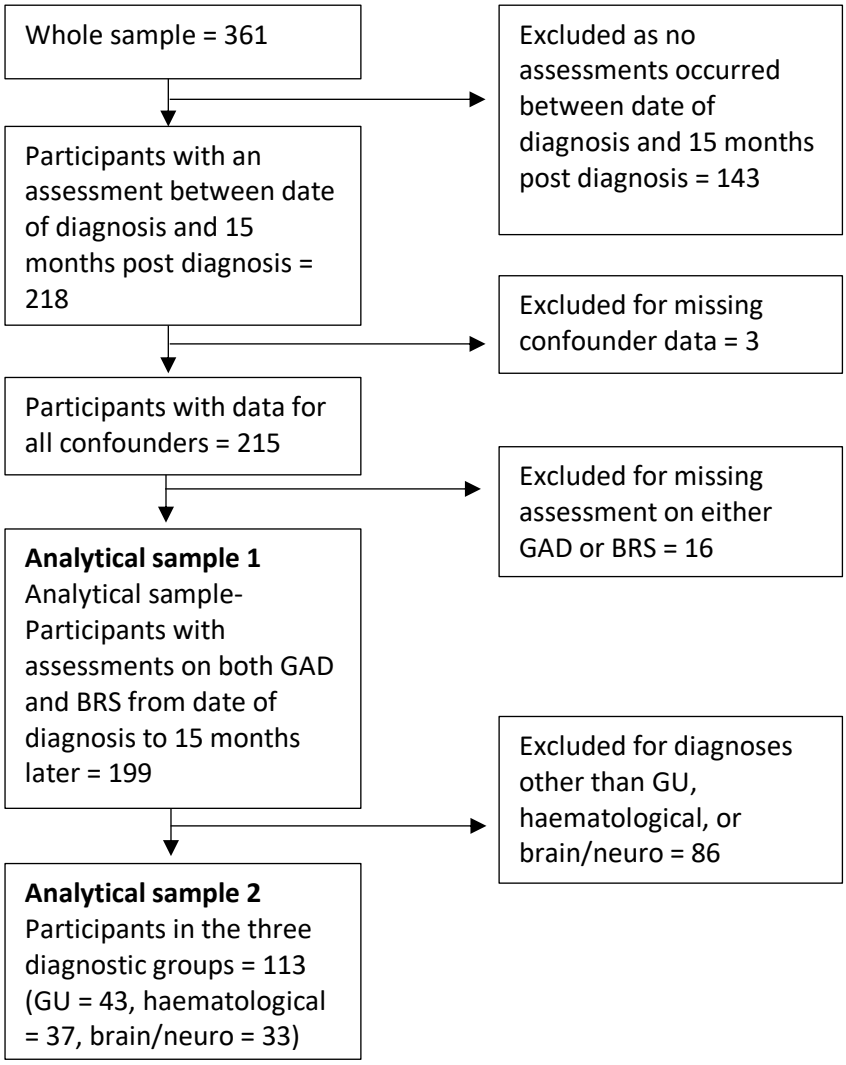
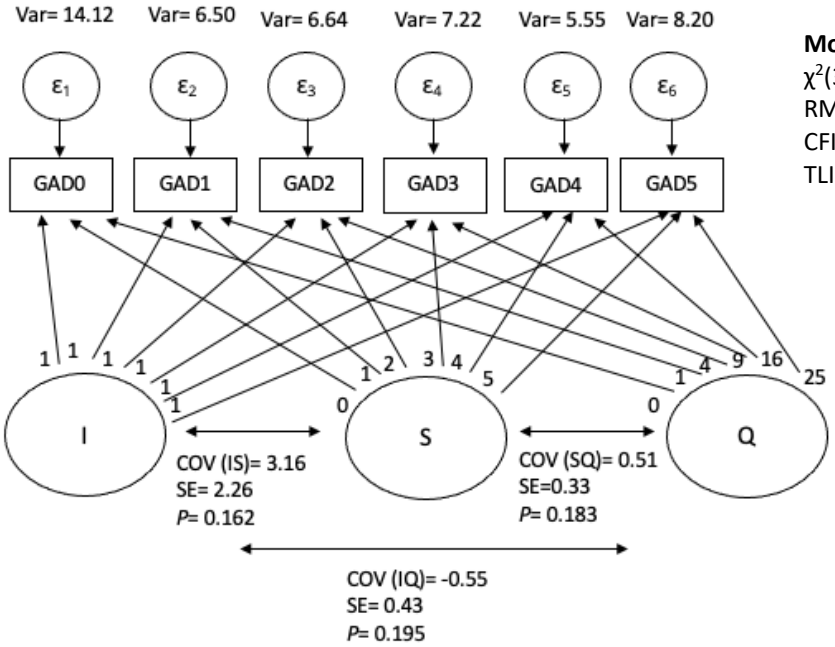


Table 1. Participant Demographics and Clinical Information

	Analytical Sample (N=199)				**Excluded Sample (N=162)**			
	Frequency (Valid Percentage)				Frequency (Valid Percentage)			
	Mean	SD	Min	Max	Mean	SD	Min	Max
Gender								
Male	114(57.3)				74(45.7)			
Female	85(42.7)				88(54.3)			
Ethnic Origin								
White	136(68.3)				103(69.1)			
Mixed/Multiple Ethnic Groups	8(4.0)				9(6.0)			
Asian/Asian British	17(8.5)				13(8.7)			
Black/African/Caribbean/Black British	29(14.6)				22(14.8)			
Other Ethnic Group	9(4.5)				1(0.7)			
Missing	-				13			
Age at diagnosis	21.2	2.2	15	24	19.8	3.7	1	25
Missing	-				5			
Diagnostic Group								
Haemato-oncology:								
Hodgkin's	27(13.6)				19(11.7)			
Non-Hodgkin's	10(5.0)				12(7.4)			
MPN	13(6.5)				17(10.5)			
Cutaneous lymphoma	10(5.0)				13(8.0)			
Head and Neck	6(3.0)				4(2.5)			
Neuro/brain	33(16.6)				36(22.2)			
Breast	2(1.0)				1(0.6)			
Gynaecological	6(3.0)				7(4.3)			
Sarcoma	3(1.5)				7(4.3)			
Skin	9(4.5)				6(3.7)			
Gastrointestinal	7(3.5)				1(0.6)			
Genitourinary	43(21.6)				21(13.0)			
Neuroendocrine Tumour	24(12.1)				17(10.5)			
Other	6(3)				1(0.6)			
Treatment Type								
Surveillance	14(7.0)				7(4.5)			
Chemotherapy Only	30(15.1)				27(17.3)			
Chemotherapy and Radiotherapy	16(8.0)				14(9.0)			
Chemotherapy and Surgery	31(15.6)				17(10.9)			
Chemotherapy and BMT	2(1.0)				3(1.9)			
Chemotherapy and Other	1(0.5)				1(0.6)			
Radiotherapy Only	5(2.5)				3(1.9)			
Radiotherapy and Phototherapy	1(0.5)				1(0.6)			
Radiotherapy and Surgery	6(3.0)				4(2.6)			
Surgery Only	63(31.7)				50(32.1)			
Surgery and Nuclear Medicine	15(7.5)				11(7.1)			
Immunotherapy Only	2(1.0)				2(1.3)			
Phototherapy Only	3(1.5)				6(3.8)			
Other	6(3.0)				7(4.5)			
Combination of 3 or more treatments	4(2.0)				3(1.9)			
Missing	-				6			

(MPN= Myeloproliferative Neoplasms, BMT= Bone Marrow Transplant)

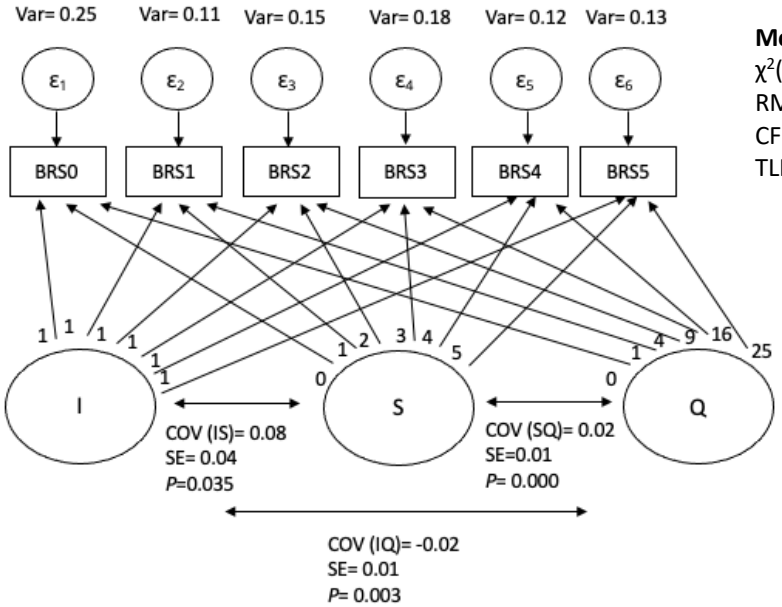
Figure 2. Quadratic growth curve model for symptoms of anxiety



Model fit indices:
$\chi^2(30) = 24.71$, $p = 0.74$
RMSEA = 0.00
CFI = 1.00
TLI = 1.00

(I= Intercept, S= Linear Slope, Q= Quadratic Slope)

Figure 3. Quadratic growth curve model for resilience

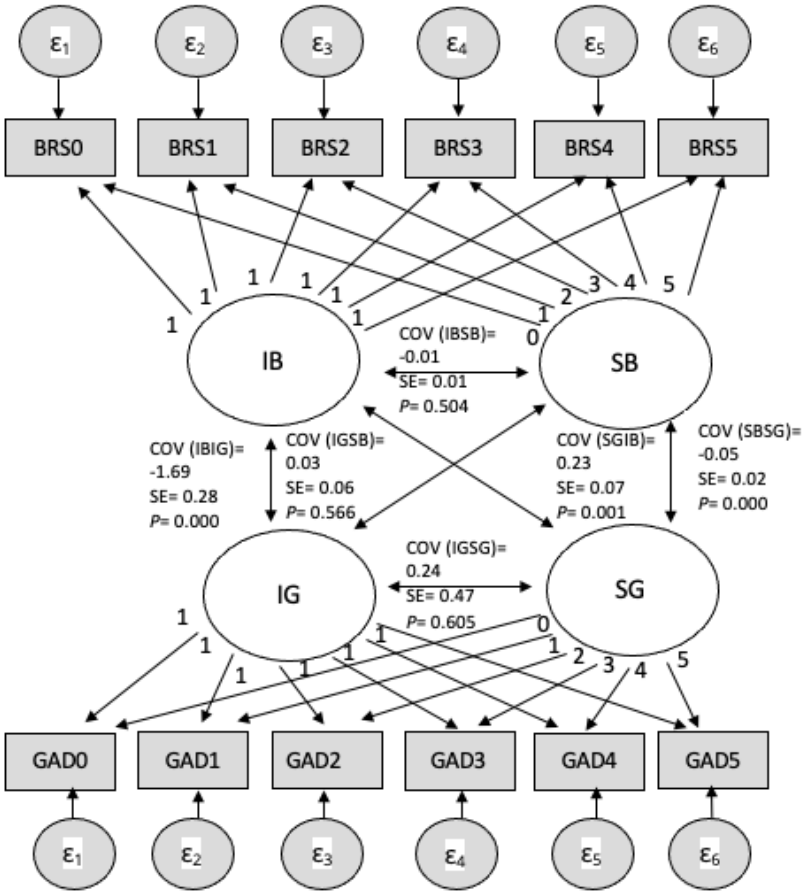


Model fit indices:
$\chi^2(30) = 35.20$, $p = 0.24$
RMSEA = 0.03
CFI = 0.99
TLI = 0.97

(I= Intercept, S= Linear Slope, Q= Quadratic Slope)

Figure 4. Sample and estimated mean plots for symptoms of anxiety and resilience

Figure 5. Parallel process model for symptoms of anxiety and resilience



Model fit indices:
$\chi^2(112) = 271.31$, $p = 0.00$
RMSEA = 0.09
CFI = 0.81
TLI = 0.77

(I= Intercept, S= Linear Slope, Q= Quadratic Slope, B= Resilience (BRS), G= Anxiety (GAD))

Figure 6. Sample and estimated mean plots for symptoms of anxiety and resilience by diagnostic group

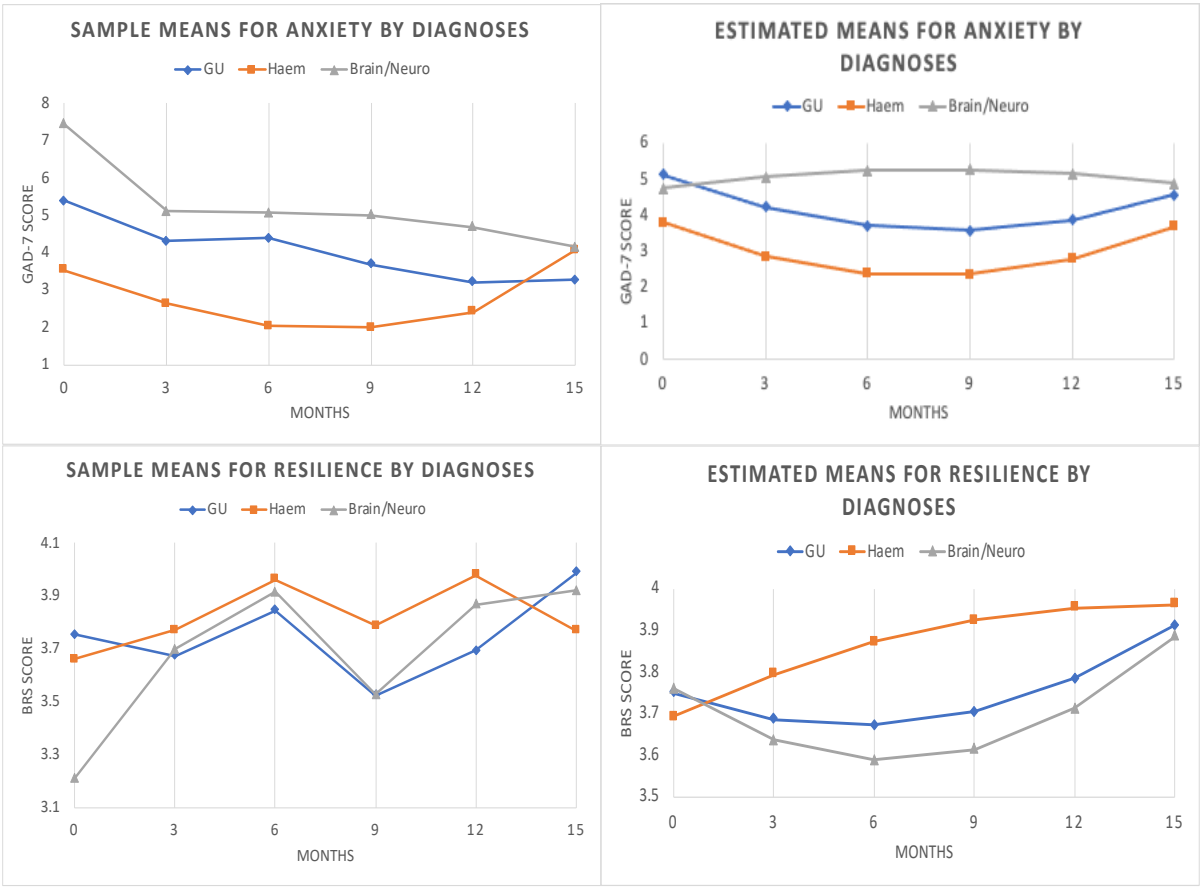


Table 2. The association between resilience and anxiety by diagnostic group

	Wald Test (W_T)		***P*-Value**		
	Diagnostic Group	**Covariance**	**SE**	**Est./SE**	**Two-tailed p-value**
Initial level of resilience (intercept) on the change of anxiety (slope)	8.71		0.013		
	GU	0.658	0.346	1.900	0.057
	Haematological	0.596	0.530	1.125	0.261
	Brain/neuro	-0.497	0.358	-1.391	0.164
Change of resilience (slope) on change of anxiety (slope)	1.84		0.397		
	GU	11.802	12.428	0.950	0.342
	Haematological	10.314	5.296	1.947	0.051
	Brain/Neuro	-1.407	6.148	-0.229	0.819

Supplement A

Models for anxiety and resilience

Analytical sample size for growth curve models of resilience and anxiety =199

Model fit information:

Model fit information		**GAD**	**GAD adjusted for confounders**	**BRS**	**BRS adjusted for confounders**	**Parallel process model**	**PP model adjusted for confounders**
Chi-square test of model fit	**Value**	15.03	24.71	12.73	35.20	132.33	271.31
	Degrees of freedom	12	30	12	30	64	112
	P-value	0.24	0.74	0.39	0.24	0.00	0.00
RMSEA	**Estimate**	0.04	0.00	0.02	0.03	0.07	0.09
	90 % CI	0.00 0.09	0.00 0.04	0.00 0.08	0.00 0.06	0.06 0.09	0.07 0.10
	Probability RMSEA ≤ .05	0.63	0.98	0.76	0.81	0.02	0.00
CFI/TLI	**CFI**	0.99	1.00	1.00	0.99	0.91	0.81
	TLI	0.99	1.00	1.00	0.97	0.90	0.77

Growth curve model results GAD:

Model Results	Estimate	SE	Est./SE	Two-tailed p-value
S WITH I	3.76	2.25	1.67	0.09
Q WITH I	-0.71	0.43	-1.64	0.10
S	0.61	0.40	1.54	0.12
Means:				
I	5.00	0.42	12.06	0.00
S	-0.46	0.27	-1.69	0.09
Q	0.07	0.05	1.24	0.21
Variances:				
I	12.17	3.80	3.20	0.00
S	-3.17	1.98	-1.60	0.11
Q	-0.11	0.08	-1.36	0.17
Residual Variances:	14.34	2.85	5.03	0.00
Gad0	6.53	1.35	4.82	0.00
Gad1	6.87	1.59	4.33	0.00
Gad2	7.57	1.59	4.77	0.00
Gad3	5.71	1.56	3.65	0.00
Gad4	9.13	3.58	2.55	0.01
Gad5				

Growth curve model results GAD adjusted for confounders:

Model Results	Estimate	SE	Est./SE	Two-tailed p-value
S WITH I	3.16	2.26	1.40	0.16

Q WITH I	-0.55	0.43	-1.30	0.20
S	0.51	0.33	1.33	0.18
Intercepts:				
I	4.88	4.34	1.13	0.26
S	0.32	2.85	0.11	0.91
Q	-0.00	0.53	-0.01	0.99
Residual				
Variances:	14.12	2.86	4.94	0.00
Gad0	6.50	1.32	4.92	0.00
Gad1	6.64	1.52	4.37	0.00
Gad2	7.22	1.54	4.70	0.00
Gad3	5.55	1.49	3.73	0.00
Gad4	8.20	3.41	2.40	0.02
Gad5	12.55	3.80	3.30	0.00
I	-2.75	1.94	-1.42	0.16
S	-0.09	0.08	-1.18	0.24
Q				

Growth curve model results BRS:

Model Results	Estimate	SE	Est./SE	Two-tailed p-value
S WITH I	0.06	0.05	1.17	0.24
Q WITH I	-0.01	0.01	-1.21	0.23
S	0.01	0.01	1.57	0.12
Means:				
I	3.61	0.06	63.97	0.00
S	-0.01	0.03	-0.29	0.78
Q	0.01	0.01	1.25	0.21
Variances:				
I	0.27	0.07	3.78	0.00
S	-0.06	0.05	-1.38	0.17
Q	-0.00	0.00	-1.55	0.12
Residual				
Variances:	0.23	0.06	3.74	0.00
Brs0	0.12	0.03	4.39	0.00
Brs1	0.14	0.04	3.91	0.00
Brs2	0.16	0.03	4.75	0.00
Brs3	0.12	0.03	3.48	0.00
Brs4	0.14	0.07	1.98	0.05
Brs5				

Growth curve model results BRS adjusted for confounders:

Model Results	Estimate	SE	Est./SE	Two-tailed p-value
S WITH I	0.08	0.04	2.11	0.04
Q WITH I	-0.02	0.01	-3.01	0.00
S	0.02	0.01	3.72	0.00
Intercepts:				
I	3.00	0.62	4.84	0.00
S	0.58	0.38	1.55	0.12
Q	-0.13	0.06	-2.19	0.03

Residual Variances:	0.25	0.06	4.53	0.00
Brs0	0.11	0.03	4.08	0.00
Brs1	0.15	0.03	4.43	0.00
Brs2	0.18	0.03	5.27	0.00
Brs3	0.12	0.03	3.54	0.00
Brs4	0.13	0.07	1.93	0.05
Brs5	0.24	0.07	3.62	0.00
I	-0.10	0.03	-3.12	0.00
S	-0.00	0.00	-3.59	0.00
Q				

Growth curve model results parallel process model:

Model Results	Estimate	SE	Est./SE	Two-tailed p-value
SB WITH IB	0.00	0.01	0.05	0.96
IG WITH IB	-1.77	0.29	-6.13	0.00
SB	0.03	0.06	0.46	0.65
SG WITH IB	0.23	0.07	3.41	0.00
SB	-0.06	0.02	-3.66	0.00
IG	0.13	0.50	0.26	0.79
Means:				
IB	3.56	0.05	69.81	0.00
SB	0.03	0.01	2.40	0.02
IG	4.89	0.38	13.06	0.00
SG	-0.18	0.09	-1.98	0.05
Variances:				
IB	0.31	0.05	6.13	0.00
SB	0.01	0.00	1.94	0.05
IG	15.46	2.74	5.64	0.00
SG	0.08	0.15	0.49	0.63
Residual Variances:	0.16	0.03	4.66	0.00
Brs0	0.13	0.03	4.99	0.00
Brs1	0.11	0.02	4.93	0.00
Brs2	0.13	0.03	4.70	0.00
Brs3	0.13	0.03	3.85	0.00
Brs4	0.10	0.05	2.14	0.03
Brs5	11.54	2.01	5.74	0.00
Gad0	6.50	1.19	5.56	0.00
Gad1	6.82	1.30	5.25	0.00
Gad2	6.21	1.34	4.62	0.00
Gad3	5.98	1.55	3.85	0.00
Gad4	10.39	2.79	3.73	0.00
Gad5				

Growth curve model results PP model adjusted for confounders:

Model Results	Estimate	SE	Est./SE	Two-tailed p-value
SB WITH IB	-0.01	0.01	-0.67	0.50

IG WITH IB	-1.69	0.28	-5.99	0.00
SB	0.04	0.06	0.57	0.57
SG WITH IB	0.23	0.07	3.47	0.00
SB	-0.05	0.02	-3.60	0.00
IG	0.24	0.47	0.52	0.61
Intercepts:				
IB	3.68	0.52	7.07	0.00
SB	-0.18	0.13	-1.34	0.18
IG	4.67	3.76	1.24	0.21
SG	0.51	0.90	0.57	0.57
Residual				
Variances:	0.16	0.04	4.44	0.00
BRS0	0.13	0.03	4.98	0.00
BRS1	0.12	0.02	4.94	0.00
BRS2	0.13	0.03	4.64	0.00
BRS3	0.16	0.04	4.10	0.00
BRS4	0.07	0.04	1.69	0.09
BRS5	11.60	1.99	5.84	0.00
Gad0	6.65	1.19	5.57	0.00
Gad1	6.82	1.29	5.30	0.00
Gad2	6.03	1.30	4.63	0.00
Gad3	6.01	1.51	3.98	0.00
Gad4	10.77	2.86	3.76	0.00
Gad5	0.30	0.05	6.01	0.00
IB	0.01	0.00	1.89	0.06
SB	15.19	2.70	5.62	0.00
IG	-0.03	0.14	-0.20	0.84
SG				

Models for anxiety and resilience by diagnostic group

Sample size N=113
Class 1= GU (n=43)
Class 2= Hodgkin's and Non-Hodgkin's (n=37)
Class 3= Brain/neuro (n=33)

Model fit information:

Model fit information	GAD by diagnoses	GAD by diagnoses adjusted for age, gender, ethnicity (mixed and other combined)	BRS by diagnoses	BRS by diagnoses adjusted for age, gender, ethnicity (mixed and other combined)	Intercept resilience on slope anxiety	Slope resilience on slope anxiety
Akaike (AIC)	2062.82	2078.25	833.31	834.24	2589.25	2581.39
Bayesian (BIC)	2125.55	2181.89	896.04	937.88	2687.41	2679.58

Sample-Size Adjusted BIC	2052.86	2061.80	823.35	817.79	2573.63	2565.80

Growth curve model results GAD by diagnoses:

Model Results		Estimate	SE	Est./SE	Two-tailed p-value
S WITH I		-5.59	7.31	-0.77	0.44
Q WITH I		1.04	1.35	0.77	0.44
S		-0.37	1.06	-0.35	0.73
Means GU:	I	5.14	0.88	5.82	0.00
	S	-1.15	0.56	-2.06	0.04
	Q	0.21	0.11	1.96	0.05
Means haem:	I	3.84	0.68	5.64	0.00
	S	-1.20	0.43	-2.80	0.01
	Q	0.24	0.10	2.38	0.02
Means brain/neuro:	I	4.60	1.75	2.63	0.01
	S	0.45	1.13	0.40	0.69
	Q	-0.08	0.19	-0.42	0.67
Variances:					
I		22.13	9.06	2.44	0.02
S		2.18	5.78	0.38	0.71
Q		0.07	0.20	0.34	0.73
Residual Variances:					
Gad0		4.61	5.21	0.89	0.38
Gad1		8.16	3.14	2.60	0.01
Gad2		5.64	1.81	3.12	0.00
Gad3		6.19	2.63	2.36	0.02
Gad4		3.25	1.90	1.72	0.09
Gad5		7.01	4.57	1.54	0.12

Growth curve model results for GAD by diagnoses adjusted for age, gender, ethnicity (mixed and other ethnicity groups combined):

Model Results		Estimate	SE	Est./SE	Two-tailed p-value
S WITH I		-5.64	7.40	-0.76	0.45
Q WITH I		0.99	1.40	0.71	0.48
S		-0.23	1.17	-0.27	0.81
Intercepts	I	3.64	5.12	0.71	0.48
GU:	S	-0.97	3.05	-0.32	0.75
	Q	0.30	0.70	0.43	0.67
Intercepts	I	1.38	5.29	0.26	0.80
haem:	S	-1.12	3.26	-0.34	0.73
	Q	0.35	0.76	0.46	0.65
Intercepts	I	2.64	4.99	0.53	0.60
brain/neuro:	S	0.53	3.17	0.17	0.87
	Q	0.02	0.73	0.02	0.98
Residual Variances:					
Gad0		3.62	5.68	0.64	0.52
Gad1		8.01	3.05	2.63	0.01
Gad2		4.98	1.91	2.61	0.01

Gad3	6.43	2.83	2.78	0.02
Gad4	3.33	2.02	1.65	0.10
Gad5	6.40	5.07	1.26	0.21
I	22.34	8.45	2.64	0.01
S	1.83	6.32	0.29	0.77
Q	0.05	0.22	0.24	0.81

Growth curve model for BRS by diagnoses:

Model Results		Estimate	SE	Est./SE	Two-tailed p-value
S WITH I		-0.02	0.15	-0.12	0.91
Q WITH I		0.01	0.03	0.21	0.83
S		0.00	0.03	0.02	0.99
Means GU:	I	3.76	0.13	28.48	0.00
	S	-0.06	0.08	-0.79	0.43
	Q	0.01	0.02	0.79	0.43
Means haem:	I	3.68	0.12	30.97	0.00
	S	0.15	0.08	1.93	0.05
	Q	-0.02	0.02	-1.40	0.16
Means brain/neuro:	I	3.75	0.22	17.23	0.00
	S	-0.13	0.17	-0.81	0.42
	Q	0.03	0.03	1.17	0.24
Variances:					
I		0.36	0.16	2.21	0.03
S		-0.00	0.17	-0.01	1.00
Q		0.00	0.01	-0.01	0.99
Residual Variances:					
Brs0		0.16	0.15	1.09	0.28
Brs1		0.13	0.04	3.15	0.00
Brs2		0.14	0.08	1.78	0.08
Brs3		0.20	0.06	3.30	0.00
Brs4		0.10	0.05	2.14	0.03
Brs5		0.12	0.15	0.81	0.42

Growth curve model for BRS by diagnoses adjusted for age, gender, ethnicity (mixed and other ethnicity groups combined):

Model Results		Estimate	SE	Est./SE	Two-tailed p-value
S WITH I		0.09	1.03	0.08	0.93
Q WITH I		-0.02	0.21	-0.07	0.94
S		0.02	0.21	0.10	0.92
Intercepts GU:	I	3.83	1.39	2.75	0.01
	S	0.40	1.43	0.28	0.78
	Q	-0.15	0.30	-0.50	0.62
Intercepts haem:	I	3.95	2.03	1.95	0.05
	S	0.54	2.35	0.23	0.82
	Q	-0.18	0.50	-0.36	0.72
Intercepts brain/neuro:	I	3.92	1.72	2.27	0.02
	S	0.25	1.95	0.13	0.90
	Q	-0.12	0.41	-0.30	0.77

Residual Variances:				
Brs0	0.25	1.00	0.25	0.80
Brs1	0.10	0.06	1.79	0.07
Brs2	0.20	0.68	0.29	0.77
Brs3	0.19	0.21	0.90	0.37
Brs4	0.11	0.08	1.36	0.18
Brs5	0.14	0.78	0.19	0.85
I	0.23	0.97	0.24	0.81
S	-0.10	1.05	-0.10	0.92
Q	-0.00	0.04	-0.10	0.92

Multiple groups model for the intercept of resilience on the slope of anxiety:

Diagnostic Group	Model Results	Estimate	SE	Est./SE	Two-tailed p-value
GU	SG ON IB	0.66	0.35	1.90	0.06
	Means:				
	I	3.73	0.12	32.31	0.00
	S	-0.00	0.03	-0.11	0.91
	Q	4.80	0.80	6.02	0.00
	Variances:				
	I	0.33	0.10	3.45	0.00
	S	0.01	0.01	1.06	0.29
	Q	14.64	3.84	3.81	0.00
	Residual Variances:				
	Gad0	7.35	2.73	2.69	0.01
	Gad1	7.42	2.87	0.59	0.01
	Gad2	6.21	2.05	3.03	0.00
	Gad3	5.62	1.75	3.21	0.00
	Gad4	2.69	1.68	1.60	0.11
	Gad5	8.97	3.46	2.59	0.01
	Brs0	0.16	0.05	2.99	0.00
	Brs1	0.13	0.04	3.05	0.00
	Brs2	0.13	0.03	4.20	0.00
	Brs3	0.19	0.05	3.96	0.00
	Brs4	0.09	0.05	1.89	0.06
	Brs5	0.15	0.11	1.33	0.18
	SG	0.21	0.12	1.68	0.09
Haemato-oncology	SG ON IB	0.60	0.53	1.13	0.26
	Means:				
	I	3.72	0.10	39.04	0.00
	S	0.05	0.03	1.82	0.07
	Q	3.12	0.57	5.48	0.00
	Variances:				
	I	0.33	0.10	3.45	0.00
	S	0.01	0.01	1.06	0.29
	Q	14.64	3.84	3.81	0.00
	Residual Variances:				
	Gad0	7.35	2.73	2.69	0.01
	Gad1	7.42	2.87	0.59	0.01

	Gad2	6.21	2.05	3.03	0.00
	Gad3	5.62	1.75	3.21	0.00
	Gad4	2.69	1.68	1.60	0.11
	Gad5	8.97	3.46	2.59	0.01
	Brs0	0.16	0.05	2.99	0.00
	Brs1	0.13	0.04	3.05	0.00
	Brs2	0.13	0.03	4.20	0.00
	Brs3	0.19	0.05	3.96	0.00
	Brs4	0.09	0.05	1.89	0.06
	Brs5	0.15	0.11	1.33	0.18
	SG	0.21	0.12	1.68	0.09
Brain/neuro	SG ON IB	-0.50	0.36	-1.39	0.16
	Means:				
	I	3.63	0.15	24.99	0.00
	S	0.03	0.04	0.69	0.49
	Q	4.71	1.16	4.07	0.00
	Variances:				
	I	0.33	0.10	3.45	0.00
	S	0.01	0.01	1.06	0.29
	Q	14.64	3.84	3.81	0.00
	Residual Variances:				
	Gad0	7.35	2.73	2.69	0.01
	Gad1	7.42	2.87	0.59	0.01
	Gad2	6.21	2.05	3.03	0.00
	Gad3	5.62	1.75	3.21	0.00
	Gad4	2.69	1.68	1.60	0.11
	Gad5	8.97	3.46	2.59	0.01
	Brs0	0.16	0.05	2.99	0.00
	Brs1	0.13	0.04	3.05	0.00
	Brs2	0.13	0.03	4.20	0.00
	Brs3	0.19	0.05	3.96	0.00
	Brs4	0.09	0.05	1.89	0.06
	Brs5	0.15	0.11	1.33	0.18
	SG	0.21	0.12	1.68	0.09

Multiple groups model for the slope of resilience on the slope of anxiety:

Diagnostic Group	Model Results	Estimate	SE	Est./SE	Two-tailed p-value
GU	SG ON IB	11.80	12.42	0.95	0.34
	Means:				
	I	3.73	0.12	31.91	0.00
	S	0.01	0.03	0.22	0.83
	Q	4.75	0.79	6.05	0.00
	Variances:				
	I	0.29	0.06	4.64	0.00
	S	-0.00	0.00	-0.72	0.47
	Q	14.17	3.49	4.06	0.00
	Residual Variances:				
	Gad0	8.83	6.87	1.28	0.29

	Gad1	8.39	4.48	1.87	0.06
	Gad2	5.89	1.85	3.19	0.00
	Gad3	5.66	1.72	3.29	0.00
	Gad4	3.01	1.75	1.72	0.09
	Gad5	10.57	6.37	1.66	0.09
	Brs0	0.18	0.04	4.13	0.00
	Brs1	0.15	0.07	1.99	0.05
	Brs2	0.14	0.05	2.55	0.01
	Brs3	0.19	0.05	4.14	0.00
	Brs4	0.13	0.06	2.37	0.02
	Brs5	0.18	0.08	2.24	0.03
	SG	0.29	0.26	1.10	0.27
Haemato-oncology	SG ON IB	10.31	5.30	1.95	0.05
	Means:				
	I	3.75	0.09	40.36	0.00
	S	0.04	0.02	1.58	0.11
	Q	3.15	0.62	5.11	0.00
	Variances:				
	I	0.29	0.06	4.64	0.00
	S	-0.00	0.00	-0.72	0.47
	Q	14.17	3.49	4.06	0.00
	Residual Variances:				
	Gad0	8.83	6.87	1.28	0.29
	Gad1	8.39	4.48	1.87	0.06
	Gad2	5.89	1.85	3.19	0.00
	Gad3	5.66	1.72	3.29	0.00
	Gad4	3.01	1.75	1.72	0.09
	Gad5	10.57	6.37	1.66	0.09
	Brs0	0.18	0.04	4.13	0.00
	Brs1	0.15	0.07	1.99	0.05
	Brs2	0.14	0.05	2.55	0.01
	Brs3	0.19	0.05	4.14	0.00
	Brs4	0.13	0.06	2.37	0.02
	Brs5	0.18	0.08	2.24	0.03
	SG	0.29	0.26	1.10	0.27
Brain/neuro	SG ON IB	-1.41	6.15	-0.23	0.82
	Means:				
	I	3.66	0.15	25.16	0.00
	S	0.02	0.04	0.36	0.72
	Q	4.81	1.20	4.01	0.00
	Variances:				
	I	0.29	0.06	4.64	0.00
	S	-0.00	0.00	-0.72	0.47
	Q	14.17	3.49	4.06	0.00
	Residual Variances:				
	Gad0	8.83	6.87	1.28	0.29
	Gad1	8.39	4.48	1.87	0.06
	Gad2	5.89	1.85	3.19	0.00
	Gad3	5.66	1.72	3.29	0.00

	Gad4	3.01	1.75	1.72	0.09
	Gad5	10.57	6.37	1.66	0.09
	Brs0	0.18	0.04	4.13	0.00
	Brs1	0.15	0.07	1.99	0.05
	Brs2	0.14	0.05	2.55	0.01
	Brs3	0.19	0.05	4.14	0.00
	Brs4	0.13	0.06	2.37	0.02
	Brs5	0.18	0.08	2.24	0.03
	SG	0.29	0.26	1.10	0.27