Screening for Patient Distress in Pediatric Cancer Care: A Recommendation from the Pan-Canadian ACCESS (Advancing Childhood Cancer Experience, Science and Survivorship) Network

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GOAL

- Characterize distress as a continuum from normative vulnerability/sadness/fear to disabling problems (e.g., anxiety, depression, panic, social isolation, existential crisis).
- Emphasize pediatric oncology impacts on patients and families across treatment and survivorship (poorer quality of life, long-term psychological outcomes, adherence challenges, family functioning).
- Highlight consequences of unrecognized distress (greater health care utilization when timely psychosocial intervention is not provided).
- Support routine and systematic psychosocial risk/distress screening as a critical standard of care (2015 Psychosocial Standard of Care for Children with Cancer).
- Identify a key implementation barrier: proliferation of instruments varying by domains, length, respondent, accessibility, and language availability, complicating tool selection for routine care.

OBJECTIVE(S)

1. To describe empirical use of available patient-/parent-proxy-reported distress and multi-symptom measures in pediatric oncology publications.
2. To summarize instrument psychometric properties relevant to screening (COSMIN-informed interpretation).
3. To evaluate clinical feasibility to guide routine implementation (cost/licensing, scoring requirements, language availability, time burden, training needs, cutoffs/follow-up guidance, and integration formats).
4. To inform Canadian pediatric oncology standardization efforts (pan-Canadian ACCESS priority; network established 2022).

STUDY METHOD

- Defined eligibility using the Population-Concept-Context (PCC) framework:
  - Population: children, adolescents, and young adults with cancer or history of childhood cancer (ages 0-21; treatment or survivorship).
  - Concept: emotional/psychological distress and/or overall symptom burden (multi-symptom measures spanning physical and emotional domains).
  - Context: pediatric oncology care.
- Included studies that:
  - Reported quantitative data and were published ≥1990.
  - Included ≥2 cancer diagnoses (non-disease specific instruments).
  - Evaluated patient-reported and/or parent-proxy-reported instruments with established scoring and quantitative results in pediatric oncology samples.
- Excluded studies that:
  - Focused on a single symptom only (e.g., pain only).
  - Used clinician-rated observational tools without standardized scoring, or measured satisfaction with care rather than distress.
  - Were case reports <10 participants, dissertations, conference abstracts, grey literature.
- Searched MEDLINE (Ovid), PubMed, and APA PsycINFO from 1990 through May 2023 using a senior librarian co-developed strategy; validated sensitivity using seed articles.
- Screened references in Covidence with automatic duplicate removal; performed dual independent title/abstract and full-text screening; resolved disagreements by consensus.
- Extracted data using a piloted, iteratively refined Excel template capturing:
  - Study design and participant characteristics;
  - Instrument features (respondent, domains, items, completion time, languages/translations, proxy availability, licensing);
  - Psychometrics (structural validity, internal consistency, test-retest, measurement error, responsiveness);
  - Feasibility (cost/free use, training/manual needs, cutoffs and follow-up guidance, electronic administration/integration).

PROJECT TIMELINES

- May 20, 2025: ACCESS psychosocial/survivorship stakeholders endorsed SSPedi as part of a minimum data set for universal screening.

RESULTS

Aim 1: Empirical use across publications

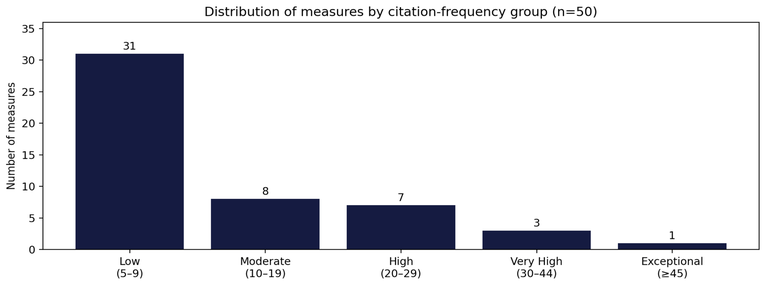
- Included 478 full-text articles meeting eligibility criteria.
- Identified 50 unique patient-/proxy-reported instruments used in ≥5 pediatric oncology publications.

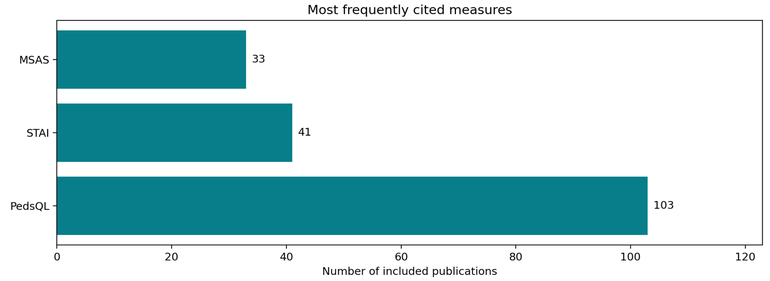
Aim 2: Psychometric properties

- Overall psychometric support was adequate for screening, although the breadth and consistency of reporting varied across instruments (see Psychometric evidence table).
- Trait-oriented measures demonstrated greater short-term stability than single-item tools, and many measures showed responsiveness to change.

Aim 3: Clinical implementation feasibility

- Most instruments were compatible with busy workflows (brief, low training burden, paper/electronic formats).
- Licensing fees and proprietary scoring requirements may prevent uptake, particularly for commonly used measures.
- Actionability of screening remains limited with fewer tools providing cutoffs and explicit follow-up recommendations.
- <u>Many measures are psychometrically adequate and feasible yet lack the ability to integrate into care pathways.</u>





Psychometric evidence summary	n / N
Internal consistency reported	46/50
α ≥ 0.70 (of those reported)	40/46 (87%)
α > 0.80 (of those reported)	28/46 (61%)
Test–retest reported (1–8 wks)	32/50
Construct validity evidence	42/50
Responsiveness evaluated	29/50
Measurement error documented	11/50
Psychometric support in ≥2 languages	38/50

Implementation indicator (n=50)	n (%)
Fee required	19 (38%)
Proprietary scoring manual/algorithm	15 (30%)
Multilingual availability	48 (96%)
English + French availability	46 (92%)
≤15 minutes to complete	46 (92%)
No specialized training required	49 (98%)
Youth self-report available	47 (94%)
Parent-proxy version available	22 (44%)
Clear cutoff scores/risk categories	19 (38%)
Used as formal screening tool	39 (78%)

IMPACT / OUTCOMES

- Demonstrate that pediatric oncology distress screening remains heterogeneous despite its recognition as a standard of care.
- Clarify that instrument proliferation is a practical barrier to consistent implementation.
- Indicate that many measures show adequate psychometrics for screening, but quality of psychometric reporting varies across instruments.
- Identify key feasibility enablers (brief completion time, minimal training, multilingual availability) alongside implementation barriers (fees, proprietary scoring, limited cutoffs/follow-up guidance).
- Implementation gap: well-validated brief tools are not uniformly adopted, supporting the need for further consideration on implementation pathway design (threshold and referral actions).
- Support movement toward standardization via stakeholder endorsement (May 20, 2025) of SSPedi as part of a minimum data set for universal distress/symptom screening (brief, multi-domain, pediatric oncology evidence, feasible across workflows).

SSPedi implementation considerations

- Use SSPedi (age-appropriate versions) as the initial, repeatable, multi-domain screener.
- Define score thresholds and follow-up pathways to prevent “screening without action”.
- Integrate screening into routine workflows (who administers, when completed, documentation, and communication back to families).
- Monitor completion rates, referral uptake, and stakeholder feedback; refine workflows to improve feasibility and equity across settings.

Limitations

- Acknowledge that citation frequency may not reflect real-world clinical implementation.
- Recognize that restricting to English-language peer-reviewed literature may omit certain tools or non-English psychometric evidence.
- Understand that institutional resources and local context may influence suitability of any single recommended tool.

ENDORSMENT

<u>SSPedi endorsed as part of a minimum data set for universal screening.</u>