







Optimizing the Measurement of Health-Related Quality of Life in Adolescents and Young Adults With Cancer

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INTRODUCTION

Adolescence and young adulthood may be characterized as a time of becoming.¹ It is a time of significant personal and professional growth and of recognizing major life milestones such as graduations, jobs, and new relationships. Nearly 90,000 adolescents and young adults (AYAs) in the United States are diagnosed with cancer annually,² experiencing it as a significantly distressing, widely disruptive, and singularly defining event in their lives. For AYAs with cancer, their “time of becoming” often is characterized by adapting to a wide-ranging number of challenges that compromise their physical, emotional, and social development and health-related quality of life (HRQOL).³⁻⁶ Their lives are less focused on life milestones and more on major treatment milestones such as completing chemotherapy, receiving “clean” scans, and returning to work or school.⁷⁻¹⁰ Among AYAs, cancer is the most common disease-related cause of death for females and second only to heart disease for males,² yet the vast majority of AYAs will survive their disease with an average 5-year survival rate of >80%.¹¹⁻¹³ Unfortunately, many AYA survivors report poorer HRQOL compared with their healthy peers,^{3,4} and are at increased risks of cancer-related infertility, financial hardship, disease recurrence, second primary cancers, and symptom burden for late and long-term effects.¹⁴⁻¹⁶

Despite the unique needs and challenges of being diagnosed with and surviving cancer as an AYA, the HRQOL experiences of AYA patients rarely are evaluated as part of clinical trials,¹⁷ and when they are assessed, they are inconsistently and incompletely captured by existing patient-reported outcome (PRO) measures. In 2013, the National Cancer Institute (NCI) held a State of the Science meeting to review and discuss current gaps in the evidence base for AYA oncology across epidemiology, basic biology, clinical trials, health services and medical care, and HRQOL research.¹³ Key findings and future directions to advance AYA oncology research were summarized in a special series of articles published in *Cancer* in the spring of 2016. Among the consensus recommendations for “next steps” from the HRQOL working group was the following: “Valid, reliable, developmentally relevant, and psychometrically robust measures of HRQOL, overall and by subdomain, are needed that cross the age spectrum and allow for studies of the full AYA age range.”¹³

More recently, the Childhood Cancer Data Initiative (CCDI) highlighted a similar need “to collect, analyze, and share data to address the burden of cancer in children and AYAs.”¹⁸ The CCDI has called for a better understanding of the barriers to PRO data collection in pediatric and AYA studies as well as the increased use of valid and reliable assessment measures. Common barriers to the completion of PROs can occur at both the patient and clinic levels. At the patient level, factors that decrease completion rates can include respondent burden, measures that are not content or culturally relevant to the patient experience, or measures that are poorly written (those that are colloquial, double-barreled, or have high literacy levels) and/or are available only in English. At the provider and/or clinic level, PROs are not always integrated into the electronic medical record or the existing workflow, paper forms can be misplaced, and the scoring of measures may

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not be interpretable or actionable. Collectively, these factors have contributed to the relatively low yield of PRO data from AYAs to inform future research and cancer care.

The goal of the current commentary was to highlight the benefit of applying scale development methodologies from the National Institutes of Health's Patient-Reported Outcomes Measurement Information System (PROMIS) to the field of HRQOL measurement among AYAs who are affected by cancer. This can be done in 2 ways: 1) using existing PROMIS measures that are relevant to the life experiences of AYA patients; and 2) using PROMIS methodologies to develop new measures for AYA patients in which gaps in important HRQOL content domains exist. PROMIS represents the state-of-the-art measurement science of PROs and is a National Institutes of Health Roadmap initiative designed to improve the assessment of PROs using modern psychometric methods.^{19,20} The main focus of the PROMIS initiative has been on developing instruments to assess health status for patients with chronic disease conditions across the age range from pediatrics to adults. Adapting the World Health Organization's tripartite framework of physical, mental, and social health,²¹ PROMIS has developed and calibrated measures with which to capture multiple areas of health and functioning²²⁻³⁰ and has extensive evidence of its validity and reliability in both pediatric and adult cancer populations.³¹⁻³⁸

HRQOL Measurement in AYAs

AYAs with cancer represent a wide range of both disease types and developmental stages, with a correspondingly wide range of HRQOL priorities. The most common cancer types among AYAs are breast cancer, thyroid cancer, hematologic malignancies, germ cell cancer, and melanoma.³⁹ Developmentally, the AYA age group captures at least 3 distinct subgroups of adolescents (aged 15-17 years), emerging adults (aged 18-25 years), and young adults (aged 26-39 years).⁴⁰ This level of disease and developmental heterogeneity results in an understandably broad range of HRQOL domains impacted by cancer and a lack of consensus regarding the standardized assessment of HRQOL for AYA patients. A recent systematic literature review identified the following core domains of HRQOL for AYAs: physical, cognitive, emotional, restricted activities, relationships with others, fertility, body image, and spirituality/outlook on life.⁴¹ In an observational study of developmentally diverse AYA patients and survivors, their most important HRQOL domains were physical function, pain, cognitive function, social support, and finances.⁴²

The importance of individual HRQOL domains varied based on the age of the subgroup and treatment status. Pain more frequently was ranked as a priority domain for AYA patients undergoing treatment compared with those who had completed treatment, and finances were more commonly ranked by older AYA patients. In what to our knowledge is the largest population-based study of HRQOL conducted in AYA patients, the National Cancer Institute's Adolescent & Young Adult Health Outcomes & Patient Experience (AYA HOPE) study,⁴³ the most common negative psychosocial life disruptions reported by AYAs (regardless of their age cohort) were finances, body image, and fertility and/or parenthood.⁴⁴

Unfortunately, existing HRQOL measures for AYAs often are limited in several important ways: content that is not specific to the unique HRQOL needs of AYAs or appropriate for their age group, questions that are not perceived to be relevant to AYAs, summary scores that lack meaningful reference values or norms, and questions that describe concepts in idiomatic or culturally biased ways or are otherwise not translatable.^{42,45-47} Thus, there is a clear need for psychometrically robust measures of HRQOL to be used with AYAs that capture meaningful constructs. Rather than reinvent the wheel, it is important to provide a clearer delineation of the appropriateness of existing HRQOL measurement frameworks and to identify any existing gaps in HRQOL domains for AYA patients with cancer. Existing measures of HRQOL may be generic, providing global evaluations of HRQOL across broad domains of physical, mental, and social health, or they may be cancer specific, incorporating disease-specific and treatment-specific aspects of HRQOL. Furthermore, these measures may be developed for and validated with pediatric and adolescent populations (eg individuals aged 8-17 years) or adult populations (individuals aged ≥ 18 years). Applying these tools for AYA research is challenging when the cohort crosses the common threshold of 18 years of age. Instead of using both pediatric and adult HRQOL measures to conduct research in AYAs, a single AYA HRQOL profile measure with a select number of short forms that captures the relevant HRQOL domains for individuals aged 15 to 39 years would be ideal.

An informal review of generic and cancer-specific HRQOL measures for pediatric and AYA populations (Table 1)⁴⁸⁻⁵⁵ identified cross-cutting themes of physical, mental, and social HRQOL. Additional areas of relevance to the HRQOL of AYAs are not easily captured by these 3 overarching themes and therefore comprise a fourth

TABLE 1. Common Measures and Domains for Assessing HRQOL in AYAs^a

Domain	MMQL Adolescent and Young Adult Forms	PedsQL 4.0 Generic and 3.0 Cancer Module	PCQL-32 and PCQL Modular	LAYA-SRQL	IOC-CS
For Ages:	13 to 20 and 21 to 45 Years	13 to 18, 18 to 25, and ≥25 Years	8 to 18 Years	18 to 39 Years	18 to 39 Years
Physical	<ul style="list-style-type: none"> Physical Body image 	<ul style="list-style-type: none"> Physical functioning Pain and hurt Nausea Perceived physical appearance 	<ul style="list-style-type: none"> Disease and treatment-related symptoms Physical Pain Nausea 	<ul style="list-style-type: none"> Vitality Fertility 	<ul style="list-style-type: none"> Body/health
Mental	<ul style="list-style-type: none"> Psychological Outlook on life Cognitive functioning 	<ul style="list-style-type: none"> Emotional functioning Procedural anxiety Treatment anxiety Worry Cognitive problems 	<ul style="list-style-type: none"> Psychological Cognitive functioning 	<ul style="list-style-type: none"> Existential/spirituality Coping Cognition/memory 	<ul style="list-style-type: none"> Personal growth Life challenges Thinking/memory problems
Social	<ul style="list-style-type: none"> Social Intimate relations 	<ul style="list-style-type: none"> Social functioning Communication 	<ul style="list-style-type: none"> Social 	<ul style="list-style-type: none"> Relationship Dependence Intimacy/sexuality 	<ul style="list-style-type: none"> Talking with parents Socializing
Other		<ul style="list-style-type: none"> School functioning 		<ul style="list-style-type: none"> Health care Education/career 	<ul style="list-style-type: none"> Health literacy Financial problems

Abbreviations: AYA, adolescent and young adult; HRQOL, health-related quality of life; IOC-CS, Impact of Cancer scale for childhood cancer survivors⁴⁸; LAYA-SRQL, Late Adolescence and Young Adulthood–Survivorship-Related Quality of Life scale⁴⁹; MMQL Adolescent, Minneapolis-Manchester Quality of Life instrument–Adolescent form⁵⁰; MMQL Young Adult, Minneapolis-Manchester Quality of Life instrument–Young Adult form⁵¹; PCQL Modular, Pediatric Cancer Quality of Life Inventory–Modular Approach⁵³; PCQL-32, Pediatric Cancer Quality of Life Inventory–32⁵²; PedsQL 3.0 Cancer Module, Pediatric Quality of Life Inventory Cancer Module⁵⁴; PedsQL 4.0 Generic, Pediatric Quality of Life Inventory Version 4.0 Generic Core Scales.⁵⁵

^aBold font indicates the presence of financial burden, body image, and fertility and/or parenthood dimensions captured by existing measures.

category for “other” HRQOL concerns (eg, school, work). To the best of our knowledge, only 2 measurement frameworks cover the entire AYA age range from 15 to 39 years: the Pediatric Quality of Life Inventory (PedsQL),⁵⁴⁻⁵⁶ which has separate, partially overlapping forms for adolescents, emerging adults, and young adults; and the Minneapolis-Manchester Quality of Life Instrument (MMQL),^{50,51} which has separate, nonparallel forms for adolescents and for young adults. It is interesting to note that several important aspects of the AYA experience (ie, financial burden,^{46,57} body image concerns,^{41,46} and fertility and/or parenthood concerns^{41,45}) are rarely and inconsistently assessed using these measures.

Advantages of PROMIS

PROMIS includes >300 measures of physical, mental, and social HRQOL from among 102 adult and 25 pediatric domains.⁵⁸ The PROMIS approach involves iterative steps of comprehensive literature searches, the development of conceptual frameworks through concept elicitation interviews, identifying and categorizing items, the qualitative assessment of items using focus groups and cognitive interviews, and the quantitative evaluation of items using techniques from both classic test theory and item response theory.^{19,20,32,59-61} To assist developers in meeting the scientific standard criteria for assessing PROs, the PROMIS investigators created an Instrument

Maturity Model.⁶² This model describes the 5 stages of instrument development from latent trait or domain conceptualization to evidence of psychometric properties in multiple clinical samples (Fig. 1).

What makes PROMIS stand apart from other established HRQOL measures is that each HRQOL domain measured by PROMIS is captured by an item bank. Other established HRQOL measures have a limited number of questions with which to assess each HRQOL construct (eg, 6 questions regarding fatigue, 8 questions regarding physical functioning, etc). The PROMIS item banks (1 bank for each PRO) include a much larger number of questions that have undergone extensive testing using qualitative and quantitative methods. Every PROMIS measure draws a select number of questions from the item bank to provide a reliable and valid assessment of the HRQOL domain of interest (eg, selecting 10 fatigue questions from the 95 fatigue questions in the PROMIS Fatigue item bank). PROMIS measures can be administered on paper or electronically as fixed-length short forms. This version of the PROMIS measure means that everyone in the study answers the same set of questions (eg, the 10-question fatigue measure). An alternate way to administer PROMIS measures is through computer adaptive testing (CAT). A CAT-based assessment individually tailors the measure to each individual based on her or his responses to each question administered. Compared with

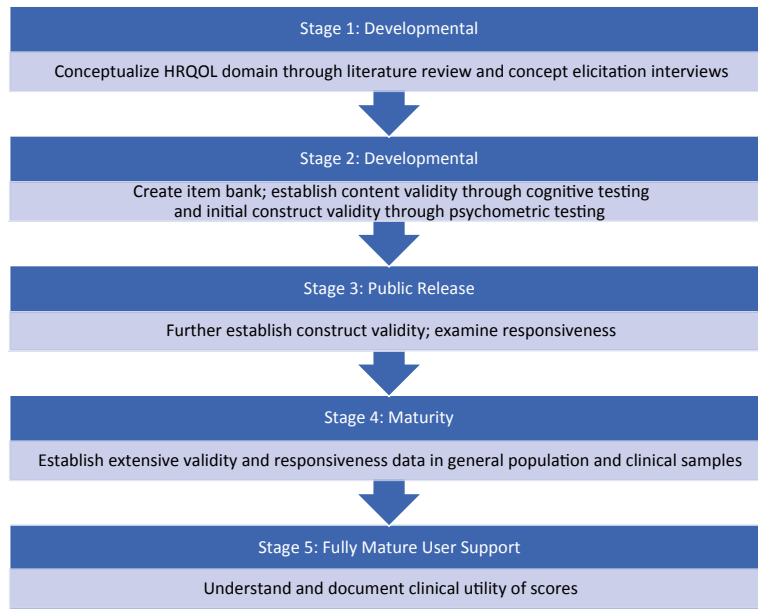


FIGURE 1. Patient-Reported Outcomes Measurement Information System (PROMIS) Instrument Maturity Model. HRQOL indicates health-related quality of life. For additional details regarding the PROMIS Instrument Maturity Model, see http://www.healthmeasures.net/images/PROMIS/PROMISStandards_Vers_2_0_MaturityModelOnly_508.pdf.

TABLE 2. AYA HRQOL Measurement Challenges and Potential Solutions

AYA HRQOL PRO Measures Need to Be...	PROMIS Provides...
Flexible	Fixed short forms or computer adaptive testing
Efficient	Minimal response burden by selecting the most relevant questions
Reliable	Includes questions that demonstrate high ability to differentiate among individual HRQOL levels
Age appropriate	Adult PROMIS questions are written at a ≤sixth-grade reading level
Relevant	Wide range of HRQOL domains can be assessed by PROMIS ^a
Comprehensible	Vetted through cognitive interviews with a diverse sample of individuals with respect to age, educational level, race and/or ethnicity, and health status
Interpretable	Uses easily interpretable T score metric with reference scores to the US general population
Translatable	Available in Spanish and other languages

Abbreviations: AYA, adolescent and young adult; HRQOL, health-related quality of life; PRO, patient-reported outcome; PROMIS, Patient-Reported Outcomes Measurement Information System.

^aThe PROMIS HRQOL domains overlap with the majority of important HRQOL domains for AYAs with the exception of financial burden, body image, and fertility and/or parenthood.

fixed-length short forms, the CAT can reduce the number of questions being administered (eg, perhaps 5 instead of 10 questions) and achieve appropriately reliable measurements. Because all PROMIS measures (fixed-length short forms or CAT-based assessments) use items selected from the same PROMIS item bank, the scores can be compared or combined together across the measures.

A particular challenge within AYA HRQOL measurement is that both pediatric and adult perspectives are represented among individuals aged 15 to 39 years. Previous testing of PROMIS measures was conducted with a broad age range (8 to 17 years and 18 to ≥99 years) and did not include a specific focus on AYAs. Linking

analyses provide an approach with which to “connect” the pediatric and adult forms in physical and emotional health domains.^{63,64} Alternatively, many of the adult items may prove reliable and valid for administration with older adolescents (those aged 15-17 years), thereby precluding the need for multiple forms. A unique strength of item banking and CAT is the flexibility in administration within a diverse sample. For example, younger and older AYAs may have different social health needs and priorities. A core set of items could be selected from within the PROMIS Social Health bank that can form a fixed-length short form across the entire AYA age range and be supplemented with additional items from the bank for specific

age groups (younger vs older AYAs) to allow for greater measurement precision. This approach would provide tailoring at the item content level while also preserving comparability of scores within the full AYA age range.

Leveraging PROMIS standards and methodology is an important next step to improve the assessment of HRQOL in AYA patients with cancer. PROMIS can serve as a blueprint for researchers interested in developing new measures that have the same high standards as PROMIS as well as extending existing PROMIS measures to new clinical populations of interest (eg, AYA patients). Accordingly, developing new item banks to assess financial burden, body image concerns, and fertility and/or parenthood concerns among AYAs will allow the creation of optimal short forms and CATs. These tools should be designed following the PROMIS scientific standards⁶⁰ and related COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN).⁶⁵⁻⁶⁸ By adhering to this rigorous stepwise approach to the development and testing of PROs, PROMIS can be used effectively to address many of the challenges that exist in measuring HRQOL among AYA patients with cancer (Table 2).

Conclusions

The NCI has issued a clear call for a more psychometrically robust approach to measurement science in AYA oncology, a call that has been echoed by the CCDI. Advances in the development and validation of PROs for use with AYAs will strengthen understanding of the patient experience and ultimately may contribute to the more efficient identification of AYA patients who are at risk of experiencing psychosocial distress and deleterious outcomes. There is growing awareness in the oncology field that PROs are valuable for capturing the patient experience to evaluate treatment efficacy and safety and should be collected routinely in trials.⁶⁹⁻⁷⁴ Additional buy-in and sustained support from funding and regulatory agencies as well as from leaders of oncology cooperative groups and review committees is needed to further catalyze PRO research in AYA oncology. A measurement system that is flexible, efficient, reliable, age appropriate, relevant, comprehensible, interpretable, and translatable holds the potential to significantly elevate AYA clinical care and research pursuits. PROMIS provides this needed framework and approach to move this field forward.

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