Hope, distress, and later quality of life among Adolescent and Young Adults with cancer

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Abstract

We aimed to explore the predictive value of screening for distress alone, hope alone, or a combination of both. In a multi-center prospective study, 37 English-speaking Adolescents and Young Adults (AYAs) with cancer and 40 parents completed validated instruments at diagnosis ("baseline") and 3–6 months later ("follow-up"). Correlated regression models described associations. Within each instrument, baseline and follow-up scores were associated. However, only a composite hope/distress score predicted all three patient-centered outcomes. Multi-dimensional screens incorporating positive and negative psychosocial constructs may predict patient-centered outcomes better than isolated, single-construct instruments.

Keywords

Patient-Centered Outcomes; Psychological Distress; Positive Psychology; Pediatric Cancer; Adolescent and Young Adult Oncology; Palliative Care

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INTRODUCTION

Dedicated psychosocial care is important for Adolescents and Young Adults (AYAs) with cancer.[1] These patients are at risk for poor mental health and quality of life (QOL), in part because cancer may disrupt normal developmental processes such as the establishment of self-identity, independence, and sexual and social relationships.[2,3]

While comprehensive psychosocial care is a standard of patient-centered oncology,[4,5] evidence-based recommendations are still in development.[6] Many guidelines focus on screening for psychological distress;[7] however, individual tools may miss significant proportions of AYAs who would benefit from psychosocial services.[8] Likewise, evaluations may be less successful if they fail to identify positive psychological resources (e.g., hope) which buffer the impact of illness.[9–11] Finally, research regarding the predictive value of screening is limited; its association with longer term patient-centered outcomes such as QOL is unclear.

We conducted post-hoc analyses of data from the "Resilience in Adolescents and Young Adults with Cancer" (RAYA) study[12–15] to explore whether distress alone, hope alone, or a composite hope/distress score was more predictive of later patient-reported QOL.

METHODS

Study Design and Participants

RAYA was a multi-center, prospective, longitudinal, mixed-methods study of English-speaking AYAs (ages 14–25) with newly diagnosed, non-Central Nervous System cancer requiring chemotherapy, and their parents.[12–15] Consecutive, eligible AYA patients were recruited from two centers (Seattle Children's Hospital and Dana-Farber/Boston Children's Hospital). The study was approved by Institutional Review Boards at both sites. All participants provided written informed consent (18 years-old) or assent with corresponding parental consent (<18 years-old).

Assessments

AYAs and their parents completed a patient-reported outcome (PRO) survey at the time of enrollment ("baseline," 14–60 days following diagnosis) and 3–6 months later ("follow-up"). Parents participated at the AYA's discretion; >1 parent per family could participate. Parents answered questions related to their own self-perceptions.

The survey included age-validated screening tools for: (a) Psychological Distress (Kessler-6 psychological distress scale)[16]; (b) Dispositional Hope, including sub-scores for "agency" (ability to generate a route to one's goals) and "pathway" (ability to initiate and maintain actions to reach those goals)[17]; and, (c) for AYAs only, Cancer-Related QOL (PedsQL 3.0 Cancer Module).[18] In each instrument, higher scores represent higher patient-report of the given construct.

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Statistical Analyses

We categorized baseline distress as low (Kessler-6 score 0–3), moderate (4–6), high (7–12), or serious (>12), and created a composite hope/distress measure by summing baseline Hope-Pathway and reversed Kessler-6 scores and converting to a 0–100 scale. Where both parents and AYAs completed the same PRO (e.g., Kessler-6 and Hope), data were pooled to augment power. We explored associations between baseline and follow-up assessments using bivariate regression modeling with robust cluster variance estimators to account for within-family or within-patient correlations. Predictors included baseline distress, hope, hope/distress composite, and cancer-related QOL total scores. Outcomes included follow-up high-to-serious distress for logistic regression modeling and total hope and cancer-related QOL total score for linear regression modeling. Each was modeled separately. All testing was two-sided and conducted at alpha <0.05 without correction for multiple comparisons.

RESULTS

Thirty-seven AYAs and 40 parents completed baseline surveys. The AYA median age was 18 years (range 14–24). Fifteen (42%) were female, and 29 (78%) were non-Hispanic White. Acute leukemia and sarcoma were their most common diagnoses. Parent median age was 48 years (range 33–66) and 36 (90%) were non-Hispanic White. Twenty-five AYAs (69%) and 33 parents (83%) remained eligible and completed the second survey. Reasons for attrition were predominantly progressive disease and/or death, although patients who participated in concurrent qualitative interviews appeared more engaged.[14]

At each time-point, at least one-third of respondents reported high-serious distress (Table 1). Hope and QOL scores were similar to population norms at each time-point.[18,19] There was a linear relationship between baseline and follow-up scores for each individual instrument (Figure 1).

Models predicting PROs at follow-up

Distress—Baseline distress, hope, and composite hope/distress, but not QOL, were associated with later high-to-serious psychological distress (Table 2). For example, every higher point of baseline distress increased the odds of later high distress (Odds Ratio [OR]=1.38, 95% CI 1.15–1.67, p<0.01) while every higher point of baseline hope lowered the odds of later high distress (OR=0.89, 95% CI 0.82–0.97, p=0.01). In contrast, associations between baseline QOL and later distress did not reach our threshold of statistical significance (OR=0.9, 95% CI 0.79–1.02, p=0.1).

Hope—All baseline PROs, including composite hope/distress, were linearly associated with hope scores at follow-up (Table 2). Baseline higher distress was associated with later lower distress (β −0.9, 95% CI −1.4, −0.4, p<0.01), higher hope (β 0.8, 95% CI 0.6–0.9, p<0.01), and higher QOL (β 0.3, 95% CI 0.1–0.6, p=0.02).

QOL—While baseline QOL was associated with later QOL (β 0.6, 95% CI 0.2–0.9, p<0.01) neither baseline distress nor hope alone was associated with later QOL (Table 2). The only PRO associated later QOL was composite hope/distress (β 0.4, 95% CI 0.1–0.8, p=0.02).

DISCUSSION

We sought to explore the role of early distress and hope as predictors of later patient-centered outcomes, and posited that combined assessment of both might be more informative than either in isolation. Unsurprisingly, early distress predicted later distress and early hope predicted later hope. But, only composite hope/distress scores predicted later QOL. Taken together, our findings suggest solely focusing on alleviating negative symptoms may be insufficient. Although psychosocial intervention research for AYAs with cancer is increasing, optimal targets for intervention design are unclear.[20] Concurrent focus on promoting positive psychological resources may hold more promise.

These findings have several important limitations. First, we conducted this post-hoc, exploratory analysis to develop hypotheses for future studies. Second, our sample was relatively small, necessitating pooled parent-child data. We lacked power to adjust for covariates, including sex and potentially collinear PROs. Although we adjusted for intra-family correlation and repeated measures, these results may be different were we to conduct analyses only among AYAs or parents. Third, participants were predominantly white, English-speaking families. Findings may not be generalizable. Fourth, in prior analyses, we found that AYA participation in qualitative interviews minimized attrition.[14] Our results may be biased; interviewed participants may have been less distressed and/or more hopeful. Finally, although a strength of this study is its prospective longitudinal design, the utility of distress/hope or other composite screening methods must be validated in future studies.

Until then, these data suggest new opportunities to promote the overall wellbeing of patients with cancer. Screening for both psychopathology and protective resources may provide targeted opportunities for interventions, thereby improving patient experiences with cancer.

Acknowledgments

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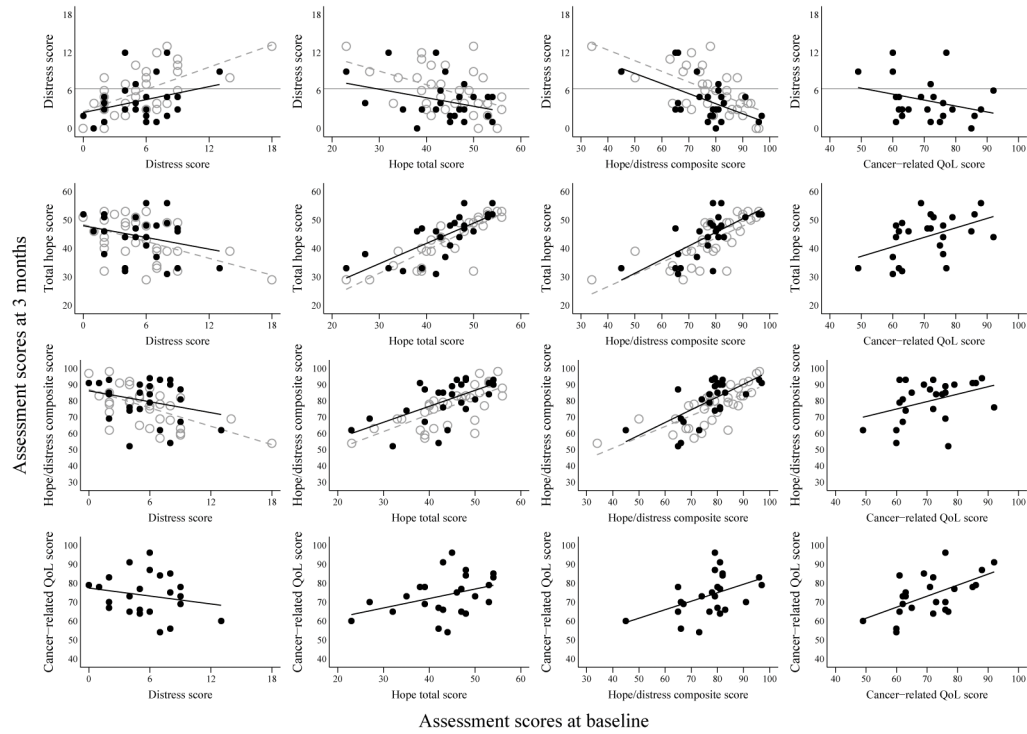
Figure 1.
AYA and parent assessments at follow-up vs. baseline assessments. Cancer-related quality of life plots include AYA only, all others include AYA and parents. Black dots = AYA, gray circles = parents.

Table 1

Adolescent and Young Adult (AYA) and Parent assessment scores at baseline and 3 month follow-up

	AYA		Parent	
	Baseline (n=37)	3 months (n=25)	Baseline (n=40)	3 months (n=33)
Kessler-6 score, mean (SD)	6 (3)	4 (3)	6 (4)	6 (4)
Range	0–14	0–12	0–18	0–13
Kessler-6 score categories, n (%)				
0–3	8 (22)	13 (52)	10 (26)	8 (24)
4–6	15 (41)	7 (28)	13 (33)	11 (33)
7–12	12 (32)	5 (20)	14 (36)	12 (36)
>12	2 (5)	0 (0)	2 (5)	2 (6)
Moderate or serious distress (Kessler-6 >6), n (%)	14 (38)	5 (20)	16 (41)	14 (42)
Hope total score, mean (SD)	44 (7)	44 (8)	45 (7)	43 (8)
Hope-Agency * score, mean (SD)	22 (4)	22 (4)	22 (4)	21 (4)
Hope-Pathway * score, mean (SD)	22 (4)	22 (4)	23 (4)	22 (4)
Hope/distress composite score **, mean (SD)	77 (11)	80 (13)	78 (12)	76 (12)
Range	45–97	52–94	34–96	54–98
PedsQL Cancer Module total score, mean (SD)	70 (12)	74 (11)	n/a	n/a
Range	49–93	54–96	n/a	n/a

*
Agency sub-score=goal-directed energy, Pathway sub-score=planning to accomplish goals

**
Higher scores suggest greater hopeful patterns of thought and lower psychological distress

Table 2

Associations between individual screening instruments at baseline and patient-centered outcomes at 3 months.

Predictors (measured at baseline)	Outcomes (measured at 3-month follow-up)											
	Odds Ratio (OR) for high/serious distress (Kessler-6>6)				Hope total score				Cancer-related QOL total score			
	n[*]	OR	95% CI	P	n[*]	Beta	95% CI	P	n[**]	Beta	95% CI	P
Kessler-6 score	57	1.38	1.15, 1.67	<0.01	57	−0.9[*]	−1.4, −0.4	<0.01	24	−0.7	−2.2, 0.8	0.34
Hope total score	57	0.89	0.82, 0.97	0.01	57	0.8[*]	0.6, 0.9	<0.01	24	0.5	0, 1	0.07
Hope/distress composite score	57	0.88	0.82, 0.95	<0.01	57	0.4[*]	0.3, 0.6	<0.01	24	0.4	0.1, 0.8	0.02
Cancer-related QOL total score	25	0.90	0.79, 1.02	0.10	25	0.3	0.1, 0.6	0.02	24	0.6	0.2, 0.9	<0.01

Legend: AYA: Adolescent and Young Adult; QOL: Quality of Life

*
AYAs and parents for all predictors except QOL.

**
AYAs only