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Distress and resilience among adolescents and young adults with cancer and their mothers: an exploratory analysis

Nancy Lau, PhD^{1,2,3}, Joyce P. Yi-Frazier, PhD¹, Kira Bona, MD, MPH^{4,5}, K. Scott Baker, MD, MS^{3,6,7}, Elizabeth McCauley, PhD^{8,9}, Abby R. Rosenberg, MD, MS, MA^{1,2,10,11}

¹Palliative Care and Resilience Research Program, Center for Clinical and Translational Research, Seattle Children's Research Institute, Seattle, WA

²Cambia Palliative Care Center of Excellence, University of Washington, Seattle, WA

³Department of Pediatrics, University of Washington School of Medicine, Seattle, WA

⁴Department of Pediatric Oncology, Dana-Farber Cancer Institute, Boston, MA

⁵Department of Pediatrics, Harvard Medical School, Boston, MA

⁶Fred Hutchinson Cancer Research Center; Seattle, WA

⁷Center for Clinical and Translational Research, Seattle Children's Research Institute, Seattle, WA

⁸Division of Child Psychiatry, Department of Psychiatry and Behavioral Sciences, University of Washington School of Medicine, Seattle, WA

⁹Center for Child Health, Behavior, and Development, Seattle Children's Research Institute, Seattle, WA

¹⁰Division of Hematology/Oncology, Department of Pediatrics, University of Washington School of Medicine, Seattle, WA

¹¹Division of Bioethics and Palliative Care, Department of Pediatrics, University of Washington School of Medicine, Seattle, WA

Abstract

The aim of this analysis was to explore intra-family longitudinal relationships in psychosocial well-being among Adolescent and Young Adults (AYAs, *Age*=17, *SD*=2.1) with cancer and their mothers using data from a multi-site, prospective, survey-based study. AYA-mother dyads (*n*=14 dyads) completed validated Patient Reported Outcomes (PROs) measures of self-perceived resilience [Connor-Davidson Resilience Scale (CD-RISC-10)] and distress [Kessler-6 psychological distress scale (K6)] at baseline (14–60 days following diagnosis) and follow-up (3–6 months later). Higher AYA distress predicted better maternal resilience, whereas higher maternal distress predicted worse AYA resilience. Thus, processes of resilience between AYAs and their mothers may differ.

Keywords

Pediatric; Adolescent/Young Adult; Family; Resilience; Psychological Distress; Patient-Centered Outcomes; Psychosocial Outcomes

INTRODUCTION

Adolescents and Young Adults (AYAs, ages 14–25) with cancer and treated in pediatric settings have unique psychosocial needs.¹ In addition to coping with their medical illness, they struggle with normal developmental challenges regarding independence, intimacy and relationships, family, and personal identity.² Survivors diagnosed with cancer as AYAs experience inferior quality of life and psychosocial outcomes compared to younger pediatric and older adult counterparts.³

Previous studies have reported a high prevalence of patient and parent psychosocial distress, changes in the AYA-parent relationship, and co-existing worries about negative long-term consequences of cancer.^{4–6} Thus, optimal psychosocial support demands an understanding of individual- and family-level perceptions at the time an AYA is diagnosed with cancer, as well as throughout the trajectory of treatment.⁷ These include both negative affective responses such as psychological distress and positive psychological resources such as resilience. Indeed, if resilience is defined as a process of harnessing resources needed to sustain individual well-being^{8–10}, it may be a key and promising target for psychosocial interventions designed to improve patient- and/or family-outcomes. Few studies have described the bidirectional impact of AYA-reported psychosocial well-being on parent-reported psychosocial well-being, and none have explicitly evaluated the role of resilience. Differing definitions of resilience exist in the literature with some theorists describing resilience as a trajectory of positive change that protects against psychological distress, and others describing resilience as adaptive functioning that develops as a consequence of exposure to stress.¹¹ We endeavored to describe novel relationships and hypothesized that parent distress would predict worse AYA resilience and similarly that AYA distress would predict worse parent resilience.

METHODS

Study Design and Participants

Data were from the “Resilience in Adolescents and Young Adults with Cancer” (RAYA) study, a multi-site longitudinal cohort study of AYAs with newly diagnosed, non-Central Nervous System cancer requiring chemotherapy, and their parents. Previous publications have described sample selection, assessment battery selection, and data collection procedures.^{12,13} The study was conducted at Seattle Children’s Hospital and at Dana-Farber/Children’s Hospital Cancer Center; IRB approval was obtained at both sites. AYAs and their parents completed Patient Reported Outcomes (PROs) at Time 1 (T1, 14–60 days following diagnosis), and then again at Time 2 (T2, 3–6 months later). All PROs are age-validated. Although one or both parents could participate, the majority of parent participants were mothers. Hence, in order to minimize heterogeneity of the sample and improve

generalizability, the current analysis focused specifically on AYA-mother dyads with two non-AYA-mother dyads excluded from analysis.

Measures

The *Connor-Davidson Resilience Scale (CD-RISC-10)*¹⁴ is a 10-item measure of resilience, personal problem solving, and approaches to adversity. The *Kessler-6 psychological distress scale (K6)*¹⁵ is a 6-item measure of psychological distress.

Statistical Analysis

Statistical analyses were conducted using IBM SPSS Statistics 24.0. Simple linear regression models were conducted with: baseline AYA distress as the independent variable and maternal resilience as the dependent variable; and with baseline maternal distress as the independent variable and AYA resilience as the dependent variable. Due to small sample size constraints and the exploratory nature of our analyses, we did not conduct multivariable analyses. All statistical tests were two-sided and conducted at the 0.05 level of significance.

RESULTS

Of the 28 AYA-parent dyads who enrolled, the 14 AYA-mother dyads (each from a single family) who completed both baseline and follow-up assessments were included in the current analysis. Demographic variables at baseline were separately examined for AYAs and mothers (Table 1). Descriptive statistics were separately examined for AYA and mother PROs at baseline and follow-up (Table 2). At each timepoint, at least one-third of AYAs and one-third of mothers reported high distress according to an established K6 cut-off score 7.¹⁵ Resilience scores were similar to established general population norms at each timepoint.¹⁴ Higher baseline AYA distress predicted *better* maternal resilience at follow-up ($\beta=0.51$, $p=.015$). Higher baseline maternal distress predicted *worse* AYA resilience at follow-up ($\beta=-0.48$, $p=.043$).

DISCUSSION

To our knowledge, this is one of the first studies to explore the roles of intra-family perceptions of resilience. Our findings suggest that parent and AYA processes of resilience may differ. AYA distress predicted better maternal resilience, whereas parent distress predicted worse AYA resilience. These data support other findings, where positive psychosocial resources are key factors of AYA, parent, and family well-being.^{16–18}

Our finding that higher AYA distress predicted greater maternal self-perceptions of resilience suggests important hypotheses about maternal resilience processes. For example, when a mother sees her AYA in distress, her natural inclination is to help. To do so, she may leverage her experience and skills in coping with challenging situations. As a result, she may appreciate her own resilience. In other words, witnessing one's "child" suffering may catalyze the process of harnessing personal and communal resilience resources. Evidence in the adult cancer literature suggests family caregivers experience perceived burden; however, caregivers' perceived preparedness to meet caregiving demands is protective for both caregivers and patients.^{19,20} In the case of pediatric and AYA cancer, parent caregivers who

feel prepared (or resilient) may provide additional resources for their young patients, in turn protecting them from later distress.

Our finding that higher maternal distress predicted worse AYA resilience was consistent with cross-sectional research suggesting that adolescents with cancer consider their parents to be their primary source of social support, and that increased parent distress may increase AYA distress.²¹ Furthermore, the crucial role that parents typically fulfill modeling appropriate attitudes, beliefs, and behaviors becomes even more consequential in modeling adaptive coping strategies to the AYA in response to their cancer diagnosis and treatment. Thus, an important focus of psychosocial interventions is family-based models of care and alleviating parental burden in order to promote parent, AYA, and whole family functioning.

Limitations of the current study include the fact that these were exploratory analyses based on a small pilot study. Thus, we did not have the statistical power to examine developmentally appropriate changes to the parent-AYA relationship as an effect of age as the AYA establishes greater self-efficacy and independence over time. We are unable to report on AYA and mother psychosocial characteristics at time-points beyond 6-months post-diagnosis. We focused on AYA-mother dyads to optimize generalizability of our findings. In so doing, we missed the voices of fathers and other caregivers. We cannot infer how these findings would relate to other caregiver relationships. Our sample also lacked racial and ethnic diversity, in part due to language availability of survey instruments, and in part due to the demographics of our populations. In addition, participant attrition limited our ability to examine prospective relationships. A previous RAYA study publication described differences in AYA engagement and found that interviewed patients were more likely to complete follow-up surveys; small sample size restricted the power to explore other potential reasons for attrition.¹³ Thus, findings should be interpreted cautiously because we may have lacked power to detect important associations and were unable to conduct multivariable analyses. A replication study should be conducted with a larger sample.

Despite the limitations discussed, this study suggests important topics of future investigation. Adequately powered future research with larger sample sizes on the multi-directional relationships between AYA psychosocial characteristics and each individual within the nuclear family is warranted, including longitudinal examinations of psychosocial characteristics such as maternal and paternal mental health, family functioning, chronic stressors, and adverse childhood events, and at timepoints beyond cancer treatment. Ultimately, such investigation has the potential to inform a comprehensive conceptual framework for family-based models of distress and resilience and psychosocial intervention research.

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Table 1.

Adolescent and Young Adult (AYA) and mother characteristics at baseline

	AYA	Mother
Female, n (%)	11 (39)	28 (100)
Age in years, mean (range)	17 (15–22)	47 (33–60)
Race, n (%)		
White	24 (86)	26 (93)
Asian, Mixed Race or Other	4 (14)	2 (7)
No answer	0 (0)	0 (0)
Hispanic or Latino Ethnicity, n (%)		
No	27 (96)	22 (79)
Yes	1 (4)	0 (0)
No answer	0 (0)	6 (21)
Cancer type, n (%)		
Acute Lymphoid Leukemia (ALL)	7 (25)	
Acute Myeloid Leukemia (AML)	3 (11)	
Germ Cell Tumor	2 (7)	
Lymphoma - Hodgkins	2 (7)	
Lymphoma - Non-Hodgkins	3 (11)	
Sarcoma (osteosarcoma, Ewings, rhabdomyosarcoma, other)	10 (36)	
Other	1 (4)	

Table 2.

Adolescent and Young Adult (AYA) and mother measure scores

	AYA		Mother	
	Baseline	Follow-Up	Baseline	Follow-Up
Connor-Davidson Resilience Scale, mean (SD)	31 (5)	31 (6)	29 (5)	29 (6)
Range	18–39	21–38	19–39	20–36
Kessler-6 score, mean (SD)	5 (3)	5 (3)	6 (4)	7 (4)
Range	0–14	2–12	1–18	0–13