

Coping and Psychological Distress in Young Adults With Advanced Cancer

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The normal transition from young adulthood to adulthood is characterized by increased responsibility for the self, autonomy in decision making, and financial independence.¹ Young adults (YAs) are also forming their self-identities and views of the world.^{1,2} Cancer disrupts these developmental tasks,³⁻⁵ creating a unique set of circumstances for coping with the cancer experience.

Younger age is consistently associated with greater psychological distress in cancer patients.⁶⁻⁹ YAs with cancer experience moderate levels of distress,^{10,11} with a significant minority meeting cut-offs for syndromal depression and anxiety.¹² Grief due to cancer-related losses has been examined as a component of psychological distress in cancer patients.¹³ Grief in bereaved individuals is a distinct syndrome characterized by disbelief, yearning for the deceased, anger, and

ABSTRACT

Background: Little is known about how young adults (YAs) cope with cancer or about the relationship between coping and psychological distress in YAs with advanced cancer.

Objectives: The goals of this study were to identify coping strategies used by YAs with advanced cancer and examine the relationship between these coping strategies and psychological distress.

Methods: Using structured clinical interviews with 53 YAs (aged 20–40 years) with advanced cancer, researchers assessed coping methods, depression, anxiety, and grief. A principal components factor analysis identified underlying coping factors. Regression analyses examined the relationship between these coping factors and depression, anxiety, and grief.

Results: Six coping factors emerged and were labeled as proactive, distancing, negative expression, support-seeking, respite-seeking, and acceptance coping. Acceptance and support-seeking coping styles were used most frequently. Coping by negative expression was positively associated with severity of grief after researchers controlled for depression, anxiety, and confounding variables. Support-seeking coping was positively associated with anxiety after researchers controlled for depression and grief.

Limitations: This study was limited by a cross-sectional design, small sample size, and focus on YAs with advanced cancer.

Conclusions: YAs with advanced cancer utilize a range of coping responses that are uniquely related to psychological distress.



Use your smartphone to read this QR code and link to an interview with Dr. Trevino. Also you can access the interview at <http://www.supportiveoncology.net/multimedia/journal-of-supportive-oncology-digital-network-video-library/single-article/psychosocial-needs-for-youth-with-cancer-different/c74fd1b7d5.html>

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Submitted for Publication: June 30, 2011; accepted August 31, 2011. Published Online: January 28, 2012 (doi: 10.1016/j.suponc.2011.08.005)

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J Support Oncol 2012;10:124-130 © 2012 Elsevier Inc. All rights reserved. doi:10.1016/j.suponc.2011.08.005

sadness that is associated with negative psychological outcomes.^{14,15} In older advanced cancer patients, grief due to losses associated with cancer was distinct from depression and associated with a greater wish to die, mental health service use, and negative religious coping.¹³ Cancer can cause significant losses in YAs and grief may be especially relevant because YAs have had limited opportunity to achieve life goals.⁵

Coping is the process of responding to a perceived threat to the self, such as a life-threatening illness like cancer.^{16,17} Problem-focused strategies (eg, planning or seeking instrumental support) intervene on the stressful situation, while emotion-focused strategies (eg, acceptance or seeking emotional support) target the emotional distress

associated with the situation.¹⁶ Both of these coping responses are generally associated with positive outcomes in cancer patients, such as better well-being and quality of life, less psychological distress, and greater growth.¹⁸⁻²⁰ A third type of coping response consists of strategies such as denial, self-blame, and venting.²¹ These strategies are associated with problematic outcomes, including greater anxiety and depressed mood as well as poorer doctor-patient relationships and quality of life.^{16,19,20,22} In survivors of testicular cancer, many of whom are YAs, participants who utilize avoidant coping strategies experience greater somatic and mental health problems than do participants utilizing more “approach”-related techniques.²³

Little is known about how YAs cope with cancer. Available research indicates that social support is an important, and often primary, coping strategy for this population.²⁴ In a sample of cancer patients aged 21-88 years, younger age was associated with greater use of support to cope.²² In a qualitative study of patients aged 16-22 with a range of cancer diagnoses, social support was a primary coping strategy.²⁴ Patients aged 19-30 years reported that established, caring relationships helped them confront the possibility of death and other losses, provided practical support, promoted normalcy, and made them feel valued.²⁵

Studies of YA samples do not assess a range of coping responses and generally do not include potentially maladaptive coping strategies such as denial and self-blame. There is also limited examination of the relationship between coping responses and psychological distress in YAs with cancer. Finally, research on coping with cancer in YAs is primarily qualitative, with limited quantitative examination of the relationship between coping and psychological distress. The goals of this study were to identify coping strategies utilized by YAs with advanced cancer and to examine the relationship between these coping strategies and psychological distress.

METHODS

Participants and Procedures

Participants included a convenience sample of 53 YA patients with advanced cancer receiving care at the Dana Farber Cancer Institute. Approval was obtained from the human subjects committee; all enrolled patients provided written informed consent. In addition, study staff obtained permission from patients' oncologists to contact patients. Structured interviews were conducted between April 2010 and March 2011 by a masters-level research assistant and a licensed clinical psychologist. Each participant completed a single interview, during which the interviewer read each question to the participant, who provided a verbal response. To participate, patients had to be 20-40 years of age and have a diagnosis of incurable, recurrent, or metastatic cancer (“advanced cancer”). Participants were excluded if they were not fluent in English, were too weak to complete the interview, and/or had scores of 5 or greater on the Short Portable Mental Status Questionnaire. Interviews lasted approximately 50–90 minutes. Participants were compensated \$25 for their participation.

Table 1

Sample Characteristics

Age, range, mean (SD)	20-40, 33.89 (5.70)
Education (Years), mean (SD)	15.49 (2.30)
Sex, n (%)	
Female	35 (66)
Male	18 (34)
Race, n (%)	
White	49 (92.5)
African American	1 (1.9)
Asian American/Pacific Islander/Indian	1 (1.9)
Hispanic	2 (3.8)
Marital status, n (%)	
Married	26 (49.1)
Other	27 (50.9)
Dependent children, n (%)	
Yes	22 (41.5)
No	31 (58.4)
Health insurance, n (%)	
Yes	52 (98.1)
No	1 (1.9)
Income, n (%)	
\$11,000-\$20,999	3 (5.7)
\$21,000-\$30,999	3 (5.7)
\$31,000-\$50,999	4 (7.5)
\$51,000-\$99,999	22 (41.5)
\$100,000 or more	11 (20.8)
Don't know	10 (18.9)
Cancer diagnosis, n (%) ^a	
Breast	21 (39.6)
Brain	7 (13.2)
Leukemia/lymphoma	5 (9.4)
Colon	3 (5.7)
Soft tissue	2 (3.8)
Other	15 (28.30)
Stage at diagnosis, n (%)	
I	2 (3.8)
II	8 (15.1)
III	11 (20.8)
IV	16 (30.2)
Unknown	16 (30.2)
Metastasis, n (%)	
Yes	28 (52.5)
No	25 (47.2)
Drug trial, n (%)	
Yes	13 (24.5)
No	40 (75.5)
Years since diagnosis, mean (SD)	3.72 (3.05)
Physical well-being, mean (SD)	6.62 (2.52)
Performance status, mean (SD)	77.55 (11.42)

^a Cancer diagnosis was dichotomized into breast cancer and other for analytic purposes.

Table 2**Descriptive Statistics and Correlations for Depression, Anxiety, Grief**

	MEAN (SD)	CORRELATIONS	
		ANXIETY	GRIEF
Depression	5.90 (5.47)	0.67*	0.52*
Anxiety	8.03 (5.30)		0.57*
Grief	23.80 (7.05)		

* $P < .01$.**Measures**

Coping. The Brief COPE is a 28-item scale used to assess coping methods.¹⁶ The scale consists of 14 subscales, with 2 items per subscale. For this study, participants indicated the extent to which they used each coping method to deal with cancer-related stress on a 4-point scale (0-3), with higher scores indicating greater use of the coping method. Responses were summed to create subscale scores.

Psychological Distress. The Prolonged Grief Disorder Scale (PG-12)^{14,15,26} is a validated measure of grief and was used to assess grief due to losses related to cancer. A total of 11 items are rated on a 5-point scale, with higher scores indicating more grief. Responses were summed to create a total grief score (Cronbach's alpha = 0.76). The McGill Quality of Life Questionnaire (MQOL)²⁷ is a 16-item self-report measure of quality of life over the previous 2 days that has been validated in individuals with life-threatening illness.²⁸ Participants rate each item using a 0-10 numerical response format. Two items were summed to assess depression ("Over the past 2 days, I have been depressed" and "Over the past 2 days, I have been sad"; Cronbach's alpha = 0.90). Two items were summed to assess anxiety ("Over the past 2 days, I have been nervous or worried" and "Over the past 2 days, when I thought of the future, I was 'not afraid'/'terrified' "); Cronbach's alpha = 0.70). Higher scores indicate greater depression and anxiety. Physical quality of life was assessed with the 1-item McGill Physical Well-Being scale ("Over the past 2 days, I have felt 'physically terrible'/'physically well' "). Higher scores indicate better physical well-being.

Performance Status. Participants' physical performance status was assessed with the Karnofsky Performance Scale, an interviewer rating scale from zero (death) to 100 (normal, no complaints, no evidence of disease; mean = 77.55; standard deviation [SD] = 11.42; range = 40-90).²⁹⁻³¹ Ratings are based on a trained rater's evaluation of the severity of symptoms and amount of assistance the participant requires to complete "normal activities."

Statistical Analysis

Descriptive analyses were conducted to characterize the sample and measures. The 14 subscales of the Brief COPE were then included in a principal components factor analysis to identify underlying factors. Regression factor scores were computed for factors having eigenvalues greater than 1. Total

scores for each factor were calculated by averaging responses on the items that loaded onto each factor. To examine frequency of use for each coping strategy, these total scores were dichotomized into ≤ 1.50 and ≥ 1.51 to correspond to "not at all"/"somewhat" and "quite a bit"/"a great deal" on the Brief COPE response scale.

Confounding variables (participant and disease characteristics) were identified through Spearman correlations predicting coping regression factor scores, depression, anxiety, and grief. Variables significantly associated with at least one coping factor regression score and the outcome measure (grief, depression, or anxiety) were added to the regression models. Psychological distress measures were then individually regressed on coping factor regression scores, controlling for the other measures of psychological distress and confounding variables.

RESULTS

Oncologists for 128 patients were contacted to request permission to recruit patients for the study; 115 patients were approved for research staff contact. In all, 27 did not return study staff calls, 6 died prior to study enrollment, and 16 did not participate for a variety of other reasons. Of the remaining 66 patients, 13 declined participation, leaving 53 (80%) study participants.

Table 1 contains demographic characteristics of the sample. The sample was primarily white (92.5%) and female (66.0%), with a mean age of 33.89 years (SD = 5.70). Approximately half of the sample was married (49.1%) and had dependent children (41.5%). More than one-third of the sample consisted of breast cancer patients (39.6%). Other diagnoses included lung, bone, pancreatic, stomach, and esophageal cancers. The relatively high proportion of participants with brain tumors (13.2%) may be attributable to the focus on patients with advanced disease. Half of the sample had current metastatic disease (52.5%) with stage III (20.8%) or stage IV (30.2%) illness at diagnosis. Mean time since diagnoses was 3.72 years (SD = 3.05). All patients had advanced disease at the time of the interview.

Table 2 includes descriptive statistics and Cronbach's alpha scores for the measures of psychological distress and correlations among these measures. Grief, anxiety, and depression were significantly correlated with each other (all $P < .01$). Table 3 contains descriptive statistics for the Brief COPE. Emotional support, acceptance, and active coping were utilized most frequently as coping responses. Substance use and denial were endorsed least often as coping responses.

Factor Analysis

The factor analysis of the Brief COPE subscales revealed 6 distinct coping factors with eigenvalues greater than 1. (See Table 3.) Proactive coping (factor 1, 18.27% of the variance) consisted of the Brief COPE subscales Active Coping, Planning, Positive Reframing, and Religion. Distancing (factor 2, 12.17% of the variance) consisted of the Brief COPE scales Humor, Religion, Behavioral Disengagement, and Instrumen-

Table 3

Eigenvalues and Factor Loadings

	MEAN (SD)	COPING FACTOR EIGENVALUE (%VARIANCE EXPLAINED) AND FACTOR LOADINGS					
		PROACTIVE	DISTANCING	NEGATIVE EXPRESSION	SUPPORT-SEEKING	RESPITE-SEEKING	ACCEPTANCE
		2.56 (18.27)	1.70 (12.17)	1.58 (11.29)	1.46 (10.43)	1.21 (8.66)	1.06 (7.54)
Active coping ($\alpha = 0.90$)	4.02 (1.88)	0.66	-0.39	-0.22	-0.12	-0.12	-0.10
Planning ($\alpha = 0.86$)	3.62 (1.96)	0.79	-0.10	-0.15	-0.01	-0.08	-0.28
Positive reframing ($\alpha = 0.84$)	3.92 (1.99)	0.69	0.35	-0.27	-0.11	0.13	-0.05
Acceptance ($\alpha = 0.80$)	4.90 (1.52)	0.36	0.15	-0.22	-0.32	0.31	0.47
Humor ($\alpha = 0.88$)	3.60 (2.37)	0.18	0.49	0.37	-0.10	-0.31	0.35
Religion ($\alpha = 0.89$)	2.36 (2.00)	0.51	0.42	-0.17	0.23	0.18	-0.29
Emotional support ($\alpha = 0.88$)	4.92 (1.50)	0.20	-0.03	-0.17	0.70	0.35	0.36
Instrumental support ($\alpha = 0.91$)	3.41 (1.87)	0.18	-0.49	0.19	0.61	-0.14	0.15
Self-distraction ($\alpha = 0.86$)	3.75 (1.85)	0.37	0.34	0.12	0.01	-0.63	0.22
Denial ($\alpha = 0.58$)	.39 (.93)	0.20	0.27	0.57	0.38	0.27	-0.29
Venting ($\alpha = 0.86$)	2.40 (1.78)	0.23	-0.31	0.54	-0.38	0.12	-0.30
Substance use ($\alpha = 0.97$)	.71 (1.57)	0.26	-0.31	0.24	-0.36	0.47	0.35
Behavioral disengagement ($\alpha = 0.98$)	1.42 (1.77)	-0.27	0.60	0.21	-0.03	0.34	-0.08
Self-blame ($\alpha = 0.83$)	1.41 (1.77)	0.39	-0.09	0.66	0.05	-0.04	0.18

Factor loadings greater than 0.40 are in bold.

tal Support, which loaded negatively on the factor. Denial, Venting, and Self-Blame loaded onto a Negative Expression factor (factor 3, 11.29% of the variance). Support-Seeking (factor 4, 10.43% of the variance) consisted of instrumental support and emotional support. Respite Seeking (factor 5, 8.66% of the variance) consisted of substance use and self-distraction, which loaded in a negative direction. Finally, the Brief COPE scale Acceptance loaded onto its own factor (factor 6, 7.54% of the variance).

Table 4 contains descriptive statistics and frequency of use for each coping factor. Acceptance coping was the most frequently used coping strategy, followed by support seeking and proactive coping. Negative expression and respite seeking were the most infrequently used coping strategies.

Regression Analysis

Table 5 contains the analyses identifying confounding variables. Race was not examined as a potential confounding

variable because the sample was more than 92% white. Dependent children and physical well-being were identified as confounding variables for the model predicting grief. Having dependent children was associated with less grief ($r_s = 0.29$; $P < .05$) and lower scores on the acceptance coping factor ($r_s = 0.31$; $P < .05$). Physical well-being was inversely associated with negative expression ($r_s = -0.29$; $P < .05$), respite seeking ($r_s = -0.33$; $P < .05$), and grief ($r_s = -0.33$; $P < .05$). These variables were included in subsequent regression analyses of grief. No confounding variables were identified for depression and anxiety.

Table 6 presents the results from the regression models predicting depression, anxiety, and grief, controlling for confounding variables and the other measures of psychological distress. Coping by negative expression was directly related to grief ($\beta = .32$; $P < .01$) after controlling for depression, anxiety, and confounding variables. Support seeking was directly related to anxiety ($\beta = .26$; $P < .05$) after controlling for depression and grief.

DISCUSSION

This study examined strategies used by YAs to cope with advanced cancer and the relationship between coping and psychological distress. In all, 6 coping factors emerged from the factor analysis. Proactive coping and distancing accounted for approximately one-third of the overall variance in coping. Acceptance coping, support seeking, and proactive coping were the most frequently utilized coping strategies. Coping by negative expression was associated with higher levels of grief, and support seeking was associated with greater anxiety after the investigators controlled for other measures of psychological distress.

Table 4

Descriptive Statistics and Frequency of use for Coping Factors

	MEAN (SD)	FREQUENCY, N (%)	
		NOT AT ALL/SOMEWHAT	QUITE A BIT/A GREAT DEAL
Proactive	1.74 (0.71)	22 (41.5)	31 (58.5)
Distancing	1.21 (0.46)	40 (75.5)	13 (24.5)
Negative expression	0.70 (0.53)	49 (92.5)	4 (7.5)
Support-seeking	2.08 (0.68)	18 (34.0)	35 (66.0)
Respite-seeking	1.12 (0.57)	48 (90.6)	5 (9.4)
Acceptance	2.45 (0.76)	7 (13.2)	46 (86.8)

Table 5**Spearman Correlations for Confounding Variables**

	COPING FACTOR					PSYCHOLOGICAL DISTRESS			
	PROACTIVE	DISTANCING	NEGATIVE EXPRESSION	SUPPORT-SEEKING	RESPIRE-SEEKING	ACCEPTANCE	DEPRESSION	ANXIETY	GRIEF
Age	0.041	0.24	0.17	-0.13	-0.029	0.017	-.02	0.10	-0.17
Education	0.19	0.19	-0.27	0.042	-0.003	0.064	-0.40**	-0.11	-0.16
Sex	0.46**	0.30*	-0.049	-0.081	-0.099	-0.24	0.012	0.21	-0.01
Marital status	0.21	0.14	0.042	-0.10	-0.07	-0.06	-0.35*	-0.07	-0.24
Dependent children	-0.14	-0.23	-0.018	0.083	0.030	0.31*	0.042	0.034	0.29*
Health insurance	0.018	0.018	-0.23	-0.018	0.19	-0.091	-0.20	-0.14	-0.19
Income	0.20	0.26	-0.18	0.094	-0.22	-0.099	-0.04	0.11	-0.10
CA diagnosis	0.30*	0.28*	-0.07	-0.17	-0.08	-0.22	-0.06	0.082	-0.20
CA stage	0.23	0.087	-0.21	-0.011	0.25	-0.21	-0.041	-0.28	-0.19
Current metastasis	-0.32*	-0.20	0.042	-0.042	-0.15	0.28*	0.078	0.11	0.036
Drug trial	-0.33*	-0.016	0.12	0.037	-0.007	0.14	0.14	-0.10	0.11
Years since diagnosis	0.00	0.15	0.002	-0.064	-0.064	0.15	0.18	-.23	0.044
Physical well-being	0.19	-0.15	-0.29*	0.18	-0.33*	0.25	-0.21	-0.27	-0.33*
Performance status	0.22	0.21	-0.22	0.084	-0.16	0.028	-0.21	0.00	-0.39**

* $P < .05$, ** $P < .01$.

Sex: 1 = male, 2 = female; marital status: 0 = not married, 1 = married; dependent children: 1 = children, 2 = no children; health insurance: 1 = yes, 2 = no; cancer diagnosis: 0 = other, 1 = breast; metastasis: 1 = yes, 2 = no; drug trial: 1 = yes, 2 = no.

The emergence of 6 coping factors indicates that YAs' strategies for coping with advanced cancer are not adequately described by the categories of problem-focused, emotion-focused, and dysfunctional coping. Categorization of coping methods in older cancer patients^{22,32} has also identified more than 3 factors, indicating that a 3-factor conceptualization oversimplifies the coping process.^{16,33} These results are notable given the prominence of problem-focused, emotion-focused, and dysfunctional coping in previous research. Clinical services that consider this complexity in coping are more

likely to serve the needs of YAs. For example, assessing a range of coping strategies will more comprehensively capture the YA coping response. Similarly, YAs may benefit from clinical interventions that recognize and promote a range of adaptive coping strategies.

Proactive coping and distancing accounted for approximately one-third of the variance in coping strategies, indicating that these are salient approaches used by YAs to cope with advanced cancer. Proactive coping is an active response that targets the problem directly. The high frequency of reported

Table 6**Adjusted Regression Analysis**

	GRIEF ^a		DEPRESSION ^b		ANXIETY ^c	
	$F(10,49) = 5.84; P < .001$		$F(8,49) = 4.73; P < .001$		$F(8,49) = 6.57; P < .001$	
	β	P	β	P	β	P
Anxiety	.35	.025	.41	.013	—	—
Depression	.24	.082	—	—	.34	.013
Grief	—	—	.28	.087	.36	.015
Dependent children	.30	.012	—	—	—	—
Physical well-being	-.080	.57	—	—	—	—
Proactive coping	.083	.46	-.20	.089	.069	.52
Distancing	-.063	.56	.12	.91	.090	.40
Negative expression	.32	.006	.006	.96	.035	.78
Support seeking	-.090	.44	.006	.96	.26	.019
Respite seeking	.062	.63	-.14	.24	-.12	.27
Acceptance	-.059	.61	.17	.14	-.16	.14

^a Outcome: grief; predictors: coping factors, depression, anxiety, dependent children, physical well-being.^b Outcome: depression; predictors: coping factor, grief, anxiety.^c Outcome: anxiety; predictors: coping factor, depression, grief.

use of proactive coping suggests that YAs often attempt to intervene directly on cancer-related stressors. However, the distancing factor suggests a potentially contradictory response in which YAs attempt to avoid confronting the cancer experience. The emergence of these coping responses as unique factors indicates that YAs are able to actively cope but may also need a reprieve from cancer. Additional research is needed to determine whether this distancing is a healthy “break” from cancer or a maladaptive avoidance that could lead to problematic outcomes such as treatment non-compliance.

The results of this study also suggest specificity in the relationship between coping and psychological distress in YAs. First, support-seeking was associated with higher levels of anxiety after investigators controlled for grief and depression, which is contrary to the well-documented benefits of social support for YAs.^{22,24,25} However, there is evidence of a positive relationship between social support and anxiety in older cancer patients.³⁴ The stress-mobilization hypothesis, in which a stressor increases both anxiety and social support, may explain this finding.^{35,36} In addition, YAs who become more anxious may receive more social support in response. Assessing the relationship between a YA’s support network and anxiety level is important.^{25,37} Some YAs may benefit from opportunities to enhance their support network through YA support groups and activities. Interventions that enable support systems to be more helpful or that help YAs manage their support systems may also be beneficial.

The relationship between more negative expression and greater grief is consistent with research in samples of older cancer patients.^{19,20} However, the emergence of this factor and its association with higher levels of grief in YAs is notable, given that previous research on this population did not assess problematic coping responses. Causality cannot be determined from this cross-sectional design. However, YAs may benefit from interventions that help them to identify personal losses and target associated grief, with a focus on reducing negative expression and promoting alternative coping strategies.

This study is limited by a cross-sectional design and small sample size, which preclude statements of causality and limiting generalizability. Regarding measurement, the measures of anxiety and depression were components of a quality of life measure, rather than validated measures of psychiatric syndromes. In addition, the measures used were

not designed for or validated on YA samples, a limitation characteristic of all psychosocial research in YA oncology at this time.⁴ The sample for this study was restricted to YAs with advanced disease³⁸ and included a broad age range that captures multiple developmental transitions. Examination of coping across disease trajectory and developmental phases within young adulthood may be important.^{39,40} Finally, a selection bias may have affected the prevalence of particular coping strategies. For example, YAs who cope by denial and substance use may be less likely to participate in a research project examining these constructs. Recruitment methods that normalize a range of coping responses, as well as measures with lower face validity, may improve YAs’ willingness to participate and endorse these coping strategies.

This study identifies important areas for future research. First, development and validation of a measure of the coping factors identified in this study would provide an assessment tool specific to YAs with cancer. Second, future research should consider other outcomes, including positive constructs (eg, positive affect or growth).⁴¹ Assessing the degree to which an individual’s goals were achieved through particular coping responses would provide a novel measure of coping outcomes in YAs.³³ Third, longitudinal evaluation of the relationship between coping and psychological distress will clarify the causal relationship between these constructs and overcome the limitations of cross-sectional research.³³

Young adulthood is a unique developmental phase that likely affects how YAs cope with cancer. In the present investigation, 6 coping factors emerged, indicating greater complexity than that captured by previous conceptualizations of coping. In addition, coping by negative expression was associated with greater grief, while support-seeking was associated with greater anxiety after investigators controlled for other measures of psychological distress. These relationships identify important targets for clinical assessment and potential effective intervention.

Conflict of Interest Disclosures: All authors have completed and submitted the ICMJE Form for Disclosure of Potential Conflicts of Interest and none were reported.

Funding/Support: This research was supported in part by the following grants (to Dr Prigerson): MH63892 from the National Institute of Mental Health and CA106370 and CA156732 from the National Cancer Institute, the Adolescent and Young Adults with Cancer Closing the Gap Fund, and the Center for Psycho-Oncology and Palliative Care Research, Dana-Farber Cancer Institute.

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