Religious/Spiritual Struggle in Young Adult Hematopoietic Cell Transplant Survivors

Stephen D.W. King, PhD,¹ George Fitchett, PhD,² Patricia E. Murphy, PhD,²
Geila Rajaei, MDiv,³ Kenneth I. Pargament, PhD,⁴ Elizabeth Trice Loggers, MD, PhD,⁵
David A. Harrison, MD, PhD,⁶ and Rebecca H. Johnson, MD⁷

Purpose: This study describes the prevalence of religious and/or spiritual (R/S) struggle in long-term young adult (YA) survivors following hematopoietic cell transplantation (HCT) as well as existential concerns (EC), social support, and demographic, medical, and emotional correlates of R/S struggle.

Methods: Data were collected as part of an annual survey of survivors of HCT aged 18–39 years at survey completion; age at HCT was 1–39 years. Study measures included measures of R/S struggle (defined as any non-zero response on the negative religious coping subscale from Brief RCOPE), quality of life (QOL), and depression. Factors associated with R/S struggle were identified using multivariable logistic regression models.

Results: Fifty-two of the 172 respondents (30%), who ranged from less than a year to 33 years after HCT, had some R/S struggle. In bivariate analysis, depression was associated with R/S struggle. In a multivariable logistic regression model, individuals with greater EC were nearly five times more likely to report R/S struggle. R/S struggle was not associated with age at transplant, time since transplant, gender, race, R/S self-identification, or medical variables.

Conclusion: R/S struggle is common among YA HCT survivors, even many years after HCT. There is a strong correlation between EC and R/S struggle. Given the prevalence of R/S struggle and its associations with EC, survivors should be screened and referred to professionals with expertise in EC and R/S struggle as appropriate. Further study is needed to determine longitudinal trajectory, impact of struggle intensity, causal relationships, and effects of R/S struggle on health, mood, and QOL for YA HCT survivors.

Keywords: religious/spiritual, struggle, survivors, hematopoietic cell transplant

Introduction

CANCER AFFECTS EIGHT TIMES as many people between the ages of 15 and 40 years as those younger than 15 years of age.¹ Furthermore, survival rates and quality of life (QOL) have not improved to the same degree in adolescents and young adults (AYAs) (aged 15–29 years) as in younger or older cancer patients.^{2,3} The emotional, physical, and social issues of AYA cancer patients present unique challenges for patients, their families, and their healthcare providers.^{2,3} AYAs are in a developmental stage in which contemplation of existential concerns (EC) is a frequent occurrence, for example, how they understand themselves, who they want to become, what difference they want to make with their lives, how they form relationships, and how they understand the

meaning of their lives. AYAs, without potentially life-limiting health challenges, exercise autonomy in creating their own identity. A cancer diagnosis during the AYA period may alter dreams, create unwanted dependence upon parents, induce concerns about chronic and/or late effects of treatment, impair developing relationships and/or vocational paths, and force confrontation with mortality.⁴ In one study, 80% of a group of 822 AYAs (aged 15–29 years) with cancer had fears or worries about dying. These fears or worries were rated as substantial (either “quite a bit” or “a great deal”) in 50% of this group.⁵

Despite the challenges it raises, a cancer diagnosis may also create an opportunity for the development of identity and wisdom in the realms of emotions, relationships, and more explicit spirituality.⁴ The EC of identity, vocation,

¹Chaplaincy, Child Life, & Clinical Patient Navigators, and ⁵Division of Clinical Research, Fred Hutchinson Cancer Research Center/Seattle Cancer Care Alliance, Seattle, Washington.

²Department of Religion, Health, and Human Values, Rush University Medical Center, Chicago, Illinois.

³University of Michigan School of Public Health, Department of Health Behavior and Health Education, University of Michigan, Ann Arbor, Michigan.

⁴Department of Psychology, Bowling Green State University, Bowling Green, Ohio.

⁶Department of Psychiatry and Behavioral Sciences, University of Washington School of Medicine, Seattle, Washington.

⁷Division of Pediatric Oncology, Department of Pediatrics, Mary Bridge Hospital/MultiCare Health System, Tacoma, Washington.

relationships, emotions, and meaning can also be grounded in fundamental spiritual and religious beliefs, practices, questions, tensions, and struggles.⁶⁻⁸

According to a Pew study, while American young adults (YAs) (aged 18–29 years) tend to be less religious, with lower reported practices of attending religious services, praying, and meditating, and lower reported rating of importance of religion and belief in God than older adults, both young and older adults reported equivalent ratings for their general spirituality (e.g., frequency of “feeling wonder about the universe”).⁹ Other studies among AYAs have found a greater importance placed upon religion and religion/spirituality.¹⁰⁻¹² There is a growing body of literature about how the religiosity/spirituality of those across the AYA age spectrum informs their coping, either during normal development or in the face of serious illness.¹⁰⁻¹⁶

Furthermore, this growing body of literature regarding the religious and/or spiritual (R/S) experiences of healthy or seriously ill in this age group reveals high religiosity^{10,11} and substantial R/S struggle.¹⁰⁻¹² This R/S struggle, also known as negative religious coping (NRC), for example, feeling abandoned, unloved, or punished by God or angry at God; having interpersonal conflict regarding religion/spirituality; and struggling with doubts and meaning,¹⁷ is associated with significant emotional distress and poorer adjustment.¹¹⁻¹³

Furthermore, a few published reports have examined R/S coping in AYAs with cancer. In a study of 484 AYAs aged 15–39 years, the 6% of patients who reported unmet spiritual counseling needs also endorsed poorer health-related QOL, specifically in the domains of fatigue ($p=0.05$), emotional functioning ($p<0.0001$), and mental health ($p<0.001$).¹⁴ In a subsequent qualitative and longitudinal study of cancer patients aged 15 to 28, AYAs used R/S coping far more than expected by the investigators. Rather than losing faith following a cancer diagnosis, they reported using religion/spirituality to help them cope and address existential issues such as finding meaning/purpose.¹⁵

Our group previously reported that YA hematopoietic cell transplantation (HCT) survivors (aged 18–39 years) experienced R/S struggle more frequently than older adults, but not necessarily more than adults in early middle age. Thirty percent of YAs (18–39 years) reported at least some R/S struggle in comparison to 36% among patients aged 40–49 years, 28% among those aged 50–65 years, and 17% among those aged 65+ years.¹⁶ The correlates and prevalence of R/S struggle within age subgroups of YAs have not yet been defined. This question is important because the YA age group encompasses different phases in the trajectory of psychosocial development, which may impact how YA patients cope with existential issues.¹⁸

In the prior study, we did not investigate EC and their relationship with R/S struggle. EC have been associated with psychological distress and physical symptoms^{19,20} in patients, but more study is needed to understand their impact in YA HCT survivors. Furthermore, to our knowledge, the relationship of R/S struggle with EC has not been studied.

We examined data from YA participants within our larger study group, both as a whole and with subgroups of YAs. The primary aim of this investigation was to study the relationship between R/S struggle and existential QOL. Secondary aims included examining the demographic, medical, emotional, and social QOL correlates of R/S struggle in YAs.

Methods

The design, population, and methodology used in this study have been previously described. Data from that primary study were collected in conjunction with an annual survey (Patient Recovery Questionnaire—PRQ) of long-term adult (≥ 18 years old) survivors of HCT at the Fred Hutchinson Cancer Research Center (FHCRC)/Seattle Cancer Care Alliance.¹⁶ This study focused on the YA survivors of HCT from that study. Study subjects were YAs aged 18–39 years at the time of the study and who had been diagnosed with cancer as a child, adolescent, or YA. Investigators worldwide define the age range for “adolescents and young adults” in widely different ways. This study used the definition of YAs from the National Cancer Institute (18–39 years).²¹ The YAs in this study may have been diagnosed as a child (aged 0–9 years), adolescent (10–18 years) (as defined by the American Psychological Association),²² or YA, but were YAs at the time of the study.

The data collection for this study was approved by the FHCRC Institutional Review Board. The response rate for the overall PRQ was 50% ($n=2113$). Of these, 79% ($n=1664$) returned the R/S module with a sufficient number of questions answered for analysis. Among these, 172 surveys were completed by YAs.

Measures

Religious or spiritual struggle. R/S struggle was measured by the NRC subscale of the Brief RCOPE.²³ Similar to earlier studies,^{24,25} this study used a dichotomous variable of no R/S struggle versus any R/S struggle as the basis for analysis.¹⁶

Quality of life. This study used four QOL measures. Two subscales were from the 36-item Short Form Health Survey (SF-36)²⁶ and 2 subscales were from the McGill Quality of Life Questionnaire.²⁷ The 2 subscales of the SF-36 survey, developed by RAND as part of the Medical Outcomes Survey to measure health-related QOL, were the general health and pain subscales. A participant may score 0 to 100 on each subscale, lower scores indicating poorer general health and more pain. The McGill QOL Questionnaire subscales measured EC (i.e., meaning, life goals, worthwhileness of life, sense of control, esteem, and life as gift) and social support (e.g., feeling supported or experiencing the world as caring, both of which could be both a result of and/or a cause of RS struggle). Individual items and subscales (average) are scored on a scale of 0 to 10 with lower scores indicating poorer QOL.¹⁶

Depression. The patient health questionnaire 8 (PHQ-8) was used to measure depression. Other than lacking an item about suicidal ideation, the PHQ-8 is identical to the PHQ-9.²⁸ Scores can range from 0 to 24. Depression was indicated by a total score of 10 or greater.^{16,29}

Graft-versus-host disease. HCT survivors had been asked if they currently had graft-versus-host disease (GVHD) in the PRQ questionnaire. Participants who indicated yes were asked to distinguish between three levels of severity: mild, moderate, or severe. A dichotomous variable was created with indication of none or mild versus moderate or

severe GVHD. This was a measure of medical issues continuing beyond transplantation.¹⁶

Other measures. The study also collected demographic and medical information. In addition, participants were asked to report their religious affiliation and R/S identification. The latter was indicated by choosing between four options: religious, but not spiritual, spiritual, but not religious, both spiritual and religious, and neither spiritual nor religious.¹⁶

Statistical analysis

The four QOL subscales were each recoded into three groups of similar size to address their skewed distribution. Categories for age, age at transplant, years since transplant, and race were also constructed. We generated descriptive information for the study variables. Subsequently, chi-square statistics were utilized to investigate bivariate associations between R/S struggle and demographic, medical, and religious variables. To examine the demographic, religious, medical, depression, and QOL correlates of R/S struggle, three nested multivariable logistic regression models were used. SPSS 19 was used to conduct all analyses.¹⁶

Results

In this study of 172 YA HCT survivors, at the time of the study, approximately a third were younger than 30 years, a third between 30 and 34 years old, and a third between 35 and 39 years. At the time of the HCT, ~20% (31) were younger than 10 years; 20% (38) were aged 10–18 years; and 60% (103) were older than 18 years. Fifty-six percent were women and 90% were white. Fifty-nine percent were Christian and 23% identified as agnostic, atheist, or having no specific religion. About one-half identified as spiritual and religious and about one-third as spiritual, but not religious. Medically, 62% were treated for leukemia. Over 40% were over 10 years post-transplant (Table 1).

Thirty percent indicated some degree of R/S struggle. None of the demographic, R/S, or medical variables were associated with R/S struggle in bivariate analysis (Table 1). Of note, there was no statistically significant difference in the association between R/S struggle and age subgroups at the time of the study or between R/S struggle and age at transplant (Table 1). Therefore, age at transplant was not included in the multivariable analysis.

Overall, the YAs reported high levels of general health (median = 65) and low levels of pain (median = 90), neither of which were associated with R/S struggle. Similarly, average scores on QOL subscale measures indicated high QOL for most participants (existential QOL, median = 8.25; social support, median = 8.5). However, R/S struggle was associated with worse scores for existential coping and social support QOL ($p = 0.000$ for each). Fourteen percent indicated moderate to severe depression. R/S struggle was significantly associated with greater depression ($p = 0.006$) (Table 2).

The multivariable modeling of correlates of R/S struggle began with R/S and demographic factors (age and race; model 1). None of these variables were associated with R/S struggle. In model 2, measures of general health, pain, and depression were added. In this model, depression was a significant predictor of R/S struggle. In model 3, measures of existential and social support QOL were added. In this model,

R/S struggle was significantly associated with existential QOL. Those with the poorest existential scores were 4.84 times as likely to indicate R/S struggle as those with the highest existential scores [odds ratio (OR) = 4.84, 95% confidence interval (CI) 1.29–18.13] (Table 3).

Discussion

This study reports the prevalence and correlates of R/S struggle using the Brief RCOPE in a sample of long-term YA (at the time of the study). Forty percent of the study sample was more than 10 years post-HCT. Thirty percent of the participants reported some R/S struggle, a percentage that is lower than the 50% reported among cancer inpatients using the Brief RCOPE.^{30–32} It is not clear if this finding reflects the difference between inpatients and outpatients or a difference between survivors and those in active treatment. Nonetheless, R/S struggle appears to be common in YA HCT survivors. Given the average years post-transplant at the time of this study, one may wonder how many of these participants have chronic R/S struggle that may have persisted since diagnosis and treatment. This is an important question because chronic R/S struggle has been associated with poorer QOL, greater depression, more physical dependency, poorer adjustment, and higher mortality.^{24,33,34} Thus, there is a pressing need for appropriate screening and intervention in this area.^{16,35}

Of particular note in this study, in a model adjusted for demographic, religion/spirituality, and other psychosocial factors, there was a strong association between R/S struggle and worse existential QOL. As noted in the introduction to this article, AYAs are already vulnerable to EC in the areas of identity, social and romantic relationships, and the meaning of their present and future lives. Adding a cancer diagnosis only intensifies and adds to these EC.⁴ Ragsdale et al. found that AYAs made meaning and hoped for recovery through the lens of religion and spirituality.¹⁵ Thus, it is not surprising that poorer existential scores and R/S struggle were positively associated in this study.

R/S struggle is frequently associated with depression in studies of cancer patients and one long-term HCT survivor study,^{16,31,32,36,37} but not always.³⁸ R/S struggle among YAs in this study was associated with depression and both the existential and social support QOL measures. In model 2 of the multivariate analysis, there was a significant association of depression with R/S struggle. However, when the McGill existential and social support QOL scores were included in model 3, this association was eliminated, suggesting that EC and social support mediate the association between R/S struggle and depression. This interpretation was supported by subsequent analysis (not shown) using Mann–Whitney tests, which revealed that survivors in the depressed group ranked significantly lower for each of the McGill existential items with p -values all <0.001 . EC (statistically significant) and lack of social support (statistical trend) are not only associated with R/S struggle but also add a further risk factor for depression, and therefore may be important additional areas of study when determining interventions to improve YA experience.

R/S struggle was not associated with any demographic variables. This finding suggests that R/S struggles affect diverse groups and supports Exline et al.'s previously published review of this literature on predictors of R/S struggle more

TABLE 1. CHARACTERISTICS BY PRESENCE OF RELIGIOUS/SPIRITUAL STRUGGLE (BRIEF RCOPE)

	<i>Total sample</i> n = 172	<i>Brief RCOPE struggle</i>		<i>Chi-square</i> p
		<i>No, n = 120 (69.8%)</i>	<i>Yes, n = 52 (30.2%)</i>	
Age at study, n (%)				0.944
18–24 years	29 (16.9)	19 (65.5)	10 (34.5)	
25–29 years	34 (19.8)	24 (70.6)	10 (29.4)	
30–34 years	50 (29.1)	36 (72.0)	14 (28.0)	
35–39 years	59 (34.3)	41 (69.5)	18 (30.5)	
Age at transplant, n (%)				0.838
0–9 years	31 (18.0)	23 (74.2)	8 (25.8)	
10–18 years	38 (22.1)	26 (68.4)	12 (31.6)	
Older than 18	103 (59.9)	71 (68.9)	32 (31.1)	
Gender, n (%)				0.744
Male	76 (44.2)	54 (71.1)	22 (28.9)	
Female	96 (55.8)	66 (68.8)	30 (31.3)	
Race, n (%)				0.398
White	154 (89.5)	109 (70.8)	45 (29.2)	
Other ^a	18 (10.5)	11 (61.1)	7 (38.9)	
Religion ^b , n (%)				0.121
Christian	102 (59.3)	73 (71.6)	29 (28.4)	
Other ^c	30 (17.4)	22 (73.3)	8 (26.7)	
No preference/none	27 (15.7)	14 (51.9)	13 (48.1)	
Agnostic/atheist	13 (7.6)	11 (84.6)	2 (15.4)	
Spirituality ^b , n (%)				0.159
Both spiritual and religious	84 (48.8)	61 (72.6)	23 (27.4)	
Religious/not spiritual	8 (4.7)	4 (50.0)	4 (50.0)	
Spiritual/not religious	60 (34.9)	38 (63.3)	22 (36.7)	
Neither spiritual nor religious	20 (11.6)	17 (85.0)	3 (15.0)	
Diagnosis ^d , n (%)				
Leukemia	107 (62.2)	74 (69.2)	33 (30.8)	
Lymphoma/Hodgkin's disease	30 (17.4)	25 (83.3)	5 (16.7)	
Multiple myeloma	4 (2.3)	2 (50.0)	2 (50.0)	
Aplastic anemia	12 (7.0)	8 (66.7)	4 (33.3)	
Myelodysplastic syndrome	11 (6.4)	7 (63.6)	4 (36.4)	
Solid tumors	2 (1.2)	1 (50.0)	1 (50.0)	
Other	6 (3.5)	3 (50.0)	3 (50.0)	
Year of diagnosis, n (%)				0.673
1977–1994	57 (33.1)	40 (70.2)	17 (29.8)	
1995–2004	52 (30.2)	34 (65.4)	18 (34.6)	
2005–2011	63 (36.6)	46 (73.0)	17 (27.0)	
Years since transplant, n (%)				0.866
2 years or less	39 (22.7)	28 (71.8)	11 (28.2)	
3–10 years	64 (37.2)	44 (68.8)	20 (31.3)	
11–20 years	41 (23.8)	30 (73.2)	11 (26.8)	
21 or more years	28 (16.3)	18 (64.3)	10 (35.7)	

^aOther includes mixed, 5 (2.9%), Black or African American, 4 (2.3%), Asian, 4 (2.3%), American Indian or Alaskan Native, 1 (0.6%), Missing 4 (2.3%).

^bChi-square was reevaluated without the category with the small cell size. Results were not different.

^cOther includes Jewish, 8 (4.7%), Buddhist, 2 (1.2%), Muslim, 2 (1.2%), Other, 11 (6.4%), LDS, 7, (4.1%).

^dMost cells were too small to calculate Chi-square.

LDS, Latter Day Saints.

generally, where demographic variables are not for the most part key predictors of R/S struggle.³⁹

This study has limitations. Because of its cross-sectional design, the analysis does not describe a trajectory of R/S struggle or determine causation between correlates and R/S struggle. Selection bias is a concern and one cannot determine how nonresponders might have responded. This study focused upon negative R/S coping (i.e., struggle) without attention to positive R/S coping. In one study of adult HCT

patients, the interaction between positive and negative styles of R/S coping impacted physical well-being.⁴⁰ The study would have benefited from more racially diverse participants. However, the 90% white participation is not that different from the racial composition of transplants internationally, for example, 79% white with 7% having no data available in 2010–2014.⁴¹ The primary measure for studying R/S struggle has been the Brief RCOPE's NRC subscale, a scale focusing primarily upon struggle with what one considers most sacred

TABLE 2. GRAFT-VERSUS-HOST DISEASE, DEPRESSION, AND QUALITY OF LIFE SCORES BY PRESENCE OF RELIGIOUS/SPIRITUAL STRUGGLE

	Total sample n = 172	Brief RCOPE struggle		Chi-square p
		No, n = 120, 69.8%	Yes, n = 52, 30.2%	
Current GVHD, n (%)				0.453 ^a
Moderate or severe	9 (5.2)	7 (77.8)	2 (22.2)	
Mild or none	163 (94.8)	113 (69.3)	50 (30.7)	
SF-36 general health (0–100) ^b , n (%)				0.122
0–50	58 (33.7)	37 (63.8)	21 (36.2)	
51–70	55 (32.0)	36 (65.5)	19 (34.5)	
71–100	59 (34.3)	47 (79.7)	12 (20.3)	
SF-36 pain (0–100) ^b , n (%)				0.516
0–68	60 (34.9)	42 (70.0)	18 (30.0)	
68.5–90	60 (34.9)	39 (65.0)	21 (35.0)	
90.5–100	52 (30.2)	39 (75.0)	13 (25.0)	
PHQ-8, n (%)				0.006
<10	148 (86.0)	109 (73.6)	39 (26.4)	
≥10	24 (14.0)	11 (45.8)	13 (54.2)	
McGill existential scale (0–10) ^b , n (%)				0.000
0–7.5	60 (34.9)	30 (50.0)	30 (50.0)	
7.6–8.9	53 (30.8)	39 (73.6)	14 (26.4)	
9–10	59 (34.3)	51 (86.4)	8 (13.6)	
McGill support scale (0–10) ^b , n (%)				0.000
0–7.5	52 (30.2)	28 (53.8)	24 (46.2)	
7.6–9	58 (33.7)	38 (65.5)	20 (34.5)	
10	62 (36.0)	54 (87.1)	8 (12.9)	

Negative religious coping subscale of the Brief RCOPE.

^aFisher's exact test used due to small cell size.

^bHigher scores on these measures indicate better health, better quality of life, or less pain.

GVHD, graft-versus-host disease; PHQ-8, patient health questionnaire 8; SF-36, 36-item Short Form Health Survey.

TABLE 3. PREDICTORS OF RELIGIOUS/SPIRITUAL STRUGGLE USING LOGISTIC REGRESSION

	Model 1			Model 2			Model 3		
	OR	95% CI	p	OR	95% CI	p	OR	95% CI	p
Spirituality (reference group, spiritual and religious)									
Religious, not spiritual	2.63	0.58–11.88	0.210	3.05	0.65–14.25	0.156	3.55	0.65–19.37	0.143
Spiritual, not religious	1.69	0.81–3.54	0.165	1.66	0.77–3.57	0.196	1.67	0.72–3.91	0.235
Neither spiritual nor religious	0.51	0.13–1.96	0.324	0.55	0.13–2.32	0.417	0.41	0.09–1.84	0.243
Age (reference group 35 through 39)									
18 through 24	1.17	0.43–3.18	0.766	1.05	0.37–2.99	0.924	1.05	0.34–3.28	0.933
25 through 29	1.08	0.42–2.81	0.870	0.96	0.36–2.61	0.940	0.73	0.25–2.16	0.569
30 through 34	0.90	0.39–2.10	0.805	0.82	0.34–2.01	0.668	0.88	0.32–2.40	0.802
White vs. other	1.62	0.56–4.72	0.373	1.36	0.44–4.17	0.596	1.52	0.45–5.12	0.495
SF-36 general health (reference group 71–100)									
Scores 51 through 70				1.77	0.68–4.56	0.241	1.96	0.68–5.67	0.214
Scores 0 through 50				1.80	0.65–5.01	0.256	1.41	0.45–4.44	0.553
SF-36 pain (reference group 100)									
68.5 through 90				1.38	0.57–3.35	0.473	1.15	0.43–3.08	0.779
0 through 68				0.85	0.31–2.33	0.747	0.52	0.17–1.62	0.261
PHQ-8 ≥ 10 (depressed)				3.16	1.23–8.15	0.017	1.37	0.46–4.06	0.573
McGill existential scale (reference group 9–10)									
Scores 7.6–8.9							1.89	0.62–5.73	0.264
Scores 0–7.5							4.84	1.29–18.13	0.019
McGill support scale (reference group 9.5–100)									
Scores 8–9							2.80	0.94–8.33	0.065
Scores 0–7.5							2.54	0.72–8.92	0.145

CI, confidence interval; OR, odds ratio.

or transcendent. Utilizing a more recently published method, the Religious and Spiritual Struggle Scale, which is broader in scope, for example, including intrapersonal domains of R/S struggle such as moral and ultimate meaning,³⁷ would be beneficial in future research.

This study fills a gap in our understanding of R/S struggle in YA survivors of HCT. The study population has a wide geographic distribution across the United States and beyond. This study supports the clinical importance of screening YAs with significant medical issues for R/S struggle, perhaps with special attention to meaning and purpose themes, given the importance of existential issues to YAs. The R/S distress screening items identified by King et al.³⁵ can provide guidance for exploring this theme clinically. Given the importance of existential issues among YAs with healthcare concerns and the findings of this study, future research should give attention to issues of meaning and purpose.

Future studies are needed to replicate or dispute these findings, including the strong associations between R/S struggle and EC and the limited associations between R/S struggle and the medical and emotional variables in YA HCT survivors. Future research should examine the longitudinal trajectory of R/S coping and R/S struggle and assess the best ways to screen for these R/S issues and existential issues in YAs. This new knowledge will inform the development of clinical interventions to address R/S struggle and promote positive transformation.^{4,42}

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Address correspondence to:

*Stephen D.W. King, PhD
Chaplaincy, Child Life, & Clinical Patient Navigators
Fred Hutchinson Cancer Research
Center/Seattle Cancer Care Alliance
PO Box 19023
Mailstop K2-231
Seattle, WA 98109*

E-mail: sking@seattlecca.org