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Posttraumatic growth among childhood cancer survivors: Associations with ethnicity, acculturation, and religious service attendance

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Abstract

This study assessed the association between ethnicity, religious service attendance (RSA), and acculturation with posttraumatic growth (PTG) in a diverse sample of 235 childhood cancer survivors (CCS). PTG scores were estimated for each ethnicity, and by level of RSA and acculturation. There was a significant curvilinear relationship (inverted U) between RSA and PTG, such that moderate levels of RSA were associated with highest PTG scores. Hispanics reported the highest PTG, and both Hispanic and Anglo cultural orientation were significantly positively associated with PTG. CCS with high or low frequency of RSA as well as Hispanic CCS who lack a strong sense of cultural identity may benefit from targeted efforts to promote psychosocial adaptation in the aftermath of cancer.

Keywords

Pediatric; Survivorship; Minorities; Posttraumatic growth; Acculturation; Religiosity; Resiliency

Survivors of child and adolescent cancers experience challenges unique to their developmental phase, such as minimized social opportunities with peers and academic delays¹. Despite these challenges, survivors often report positive psychosocial changes as a result of their cancer experience². These changes, referred to as posttraumatic growth (PTG), may include reassessed priorities, improved relationships, and an increased sense of meaning in one's life³. PTG has been positively associated with health promoting behaviors, such as seeking disease-specific medical follow-up care⁴ and decreased participation in risky behaviors such as substance use⁵.

Numerous factors are associated with PTG among cancer survivors, including sociodemographic characteristics. For example, adult African American and Hispanic cancer survivors report higher levels of PTG than non-Hispanic whites⁶. Although studies have assessed PTG (or similar constructs such as benefit finding, the perception of positive changes as a result of challenging experiences) among adolescent and young adult

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survivors of childhood cancer, this literature tends to consist largely of non-Hispanic white samples^{2,7}. More research is needed on younger survivors among racial/ethnic minorities.

Cultural factors may explain some of the racial/ethnic variation in PTG. For example, Latin cultures may emphasize individuation from the family at a later age, while maintaining closeness with one's family, which is a major source of social support among young adults and can contribute to psychosocial and physical health^{8,9}. Acculturation refers to cultural changes experienced by immigrants in a new cultural context. This is a bi-dimensional process whereby an individual's orientation toward the dominant culture and his/her heritage culture may be independent; that is, strong orientation toward one culture does not necessarily indicate less orientation toward the other¹⁰. Cultural identification may impact perception of and adjustment to illness and should be considered when assessing psychosocial health outcomes among diverse populations¹¹. For example, in a multiethnic sample of young adults, ethnic identity was associated with resiliency after other (non-cancer) childhood stressors¹². Arpa Wong and colleagues found no differences in PTG by ethnicity alone, but when including language spoken at home (one aspect of acculturation), Hispanics who spoke English in the home reported lower levels of PTG than did their non-Hispanic white or Hispanic/Spanish-speaking counterparts¹³. However, language spoken at home is just one component of acculturation, so broader measures need to be considered. Anglo (non-Hispanic white American) orientation among Hispanic adolescents has been positively associated with depression¹⁴, which has been negatively correlated with PTG¹³, suggesting that Anglo orientation may not be supportive of mental health among Hispanic youth.

Aspects of religiosity may also influence psychological responses to traumatic health events. Further, there could be a reciprocal relationship between religiosity and PTG. For example, pre-trauma religiosity may be associated with increased willingness to process traumatic events and address questions of personal meaning; likewise, traumatic experiences can lead individuals to seek out religion as a means of coping¹⁵. Thus, religious individuals may be characterized by an increased readiness to confront existential questions in the face of difficulty, which underlies the development of PTG¹⁶. In one study, religiosity was positively associated with PTG among adult breast cancer survivors⁶. It is unclear whether religiosity has a similar relationship with PTG among childhood cancer survivors (CCS).

This study examined differences in PTG by ethnicity, acculturation, and religious service attendance (RSA) (one aspect of religiosity¹⁷) among CCS. It was hypothesized that PTG would be highest among Hispanic participants, would be positively associated with Hispanic acculturation and RSA, and would be negatively associated with Anglo acculturation.

METHODS

PARTICIPANTS AND PROCEDURES

Participants were recruited to participate in Project Forward, a study of health-related risk and protective factors among CCS⁴. CCS who were diagnosed with cancer at age 18 or younger, were selected from the Los Angeles Cancer Surveillance Program (CSP) (the Surveillance, Epidemiology, and End Results (SEER) cancer registry for Los

AngelesCounty). Additional selection criteria included being diagnosed between 2000–2007 at two major children’s hospitals in LA County, and who were between 14–25 years of age at the time the study was conducted in 2009. All cancer types were included except for Hodgkin Lymphoma because they were included in another registry-based study and, in order to reduce patient burden, the registry does not permit multiple studies to contact a patient during a given year.

Treating physicians of all sampled CCS were informed of the study by letter and given the opportunity to deny permission to contact their patient if they felt it would be inappropriate for any reason (though none requested exclusion). Surveys and study information were mailed to participants in English or Spanish (for those with Spanish surnames), with the additional option to complete the survey online or over the phone. Materials were mailed directly to CCS who were 18 or older at the time of the study. An introductory letter contained the elements of informed consent, but a signed consent form was not required. For those who were under 18, materials were mailed to their parents who provided written consent for their child to participate. In addition the child signed an assent form. Follow-up calls were made to non-respondents and second packets/reminder post cards were sent when needed. Participants received \$20 and entry into a lottery for a \$300 prize for completing the survey. All study procedures were approved by the California Committee for the Protection of Human Subjects, California Cancer Registry, and by human subjects committees at the University of Southern California, CHLA, and Miller Children’s Hospital.

The final sample consisted of 235 participants. 27 responded to the online survey, 4 completed the survey via telephone, and the rest completed a mailed-in paper survey. This represented a 50% total response rate (which is higher than other cohorts of adolescent and young adult cancer survivors that included more recently diagnosed participants, which would result in more recent and reliable registry contact information)²⁸. The participation rate (excluding ineligible cases that were never reached through any recruitment efforts) was 61%.

MEASURES

Demographic information including age, sex, and age at diagnosis, as well as treatment intensity were obtained from the cancer registry. Ethnicity (Hispanic, non-Hispanic white, Other) was self-reported in the survey.

Treatment Intensity—Treatment intensity was calculated using the Intensity of Treatment Rating Scale 2.0 (ITR-2), which uses cancer registry data and medical chart reviews (including cancer type and stage of disease) to categorize cases into four levels of treatment intensity: 1=least intensive (e.g., surgery only), 2=moderately intensive (e.g., chemotherapy or radiation), 3=very intensive (e.g., two or more treatment modalities), 4=most intensive (e.g., relapse protocols)¹⁸. This measure was validated using two sets of pediatric oncologists external to the institution that developed the scale. Additionally, inter-rater reliability for 12 patients of varying treatment intensities was assessed by a third group of raters, revealing high agreement (median agreement $r=0.87$)¹⁸.

Posttraumatic growth—A 10-item short form¹⁹ of the Posttraumatic Growth Inventory (PTGI) by Tedeschi and Calhoun²⁰ was used to measure PTG, with simplified language for younger respondents. Participants were prompted to indicate the degree to which change was experienced as a result of having had cancer in various domains, such as “I changed my priorities about what is important in life,” “I have a greater appreciation for the value of my own life,” “I have a greater sense of closeness with others,” and “I discovered that I’m stronger than I thought I was.” Possible responses range from 1=“did not experience any change” to 6=“very great degree” of change. However, two items in this inventory address aspects of spirituality or religiosity and since an aspect of religiosity (RSA) was an explanatory variable of interest in this study, these items were dropped from the total PTG score in multivariable analyses, resulting in a total of 8 items (total score range: 8–48). The summed score across these 8 items was used in all multivariable analyses, with higher scores indicating higher levels of PTG. Cronbach’s alpha was 0.89 for the full scale including the spirituality/religiosity items, and 0.88 when excluding those items.

Acculturation—If a respondent self-identified as Hispanic they were directed to respond to a 13-item measure of acculturation, a shortened version of the Acculturation Rating Scale for Mexican Americans-II by Cuellar, Arnold, and Maldonado²¹ (the word “Mexican” was changed to “Hispanic” to be more broadly applicable). This shortened scale was taken from a larger cohort study of Latino adolescents in Los Angeles County²². Questions about orientation toward each culture (Hispanic and Anglo) are asked separately, based on the conceptualization of acculturation as a bidimensional process¹⁰. The shortened scale in this study included items focused primarily on language and behavioral aspects of acculturation such as “I enjoy speaking Spanish”, “I write letters in English”, “I enjoy Spanish language TV”, or “My friends are of Anglo or White origin”. Responses ranged from 1- “Not at all” to 5- “Almost always/extremely often.” Possible range of the summary scores were 6–30 (based on 6 items) for the Hispanic subscale and 6–35 (based on 7 items) for the Anglo subscale. Cronbach’s alpha for the Hispanic and Anglo subscales from the abbreviated scale was 0.92 and 0.68, respectively.

Religious service attendance—Attendance was measured with a single item, “how often do you attend religious services?”, with answers ranging from 0=never, 1=every few years, 2=several times a year, 3=2–3 times a month, 4=at least once a week, or don’t know. For analysis, “Don’t know” was grouped with the lowest category.

STATISTICAL ANALYSES

Descriptive statistics were calculated for PTG and each explanatory variable. PTG was negatively skewed and variable transformation (e.g. logarithm, cubed, inverse) was unable to correct for violated assumptions of linear regression. Therefore, ordinal logistic regression (proportional odds) was used in analyses, an approach that has been used previously when analyzing PTG among CCS⁷. A likelihood ratio test indicated the proportional odds assumption was met (H_0 =explanatory variables display a consistent odds ratio (OR) across each interval of the outcome variable, $p=0.86$).

The association between continuous explanatory variables (RSA, acculturation, age at diagnosis) and PTG was assessed using locally weighted scatterplot smoothing (LOWESS)²³, a desirable method because it tends to follow the data. These diagnostics demonstrated that there was a linear relationship between all explanatory variables and PTG except for religiosity, for which there appeared to be a curvilinear relationship; therefore, a quadratic term for this variable was added to the multivariable models. Acculturation was examined only among Hispanics in a separate model, which included the Hispanic and Anglo subscales as independent variables.

Multivariable models included covariates (age at diagnosis, treatment intensity, sex) that were chosen a priori based on relevance to PTG among CCS, as established in previous literature^{2,13,24}. Language in which survey was completed was not included as a covariate because only 6 participants completed the survey in Spanish. The dependent variable was PTG (ordinal categories determined by quartiles), and independent variables included ethnicity, RSA, and the Hispanic and Anglo acculturation subscales. The interaction of Hispanic and Anglo orientation was also tested to explore the joint effect on PTG, given that biculturalism (high Hispanic orientation and high Anglo orientation) has been associated with health outcomes²⁵. In order to provide meaningful and interpretable results, we estimated probabilities of reporting the highest quartile PTG score (scores = 44) for variables that were significant at the $p < 0.05$ level, which were calculated using the estimates from each multivariable analysis by simulation using 1000 randomly drawn sets of estimates from a sampling distribution with the mean equal to maximum likelihood point estimates, variance equal to the variance-covariance matrix of the estimates, and covariates set at their mean values²⁶. Listwise deletion resulted in 21 missing across all variables for a total sample size of 214 in the multivariable model including all subjects and 112 in the Hispanic-only model. All analyses were performed using Stata version 14²⁷.

RESULTS

Characteristics of respondents and non-respondents were compared using registry data and no differences were found with respect to current age ($p = .65$), age at diagnosis ($p = .28$), or ethnicity ($p = .71$), although females were more likely to respond than males (56.4% vs. 44.8%; $p < .05$). Half the sample was female and just over half were Hispanic (Table 1). PTG scores ranged from 8–48 with a median of 40. On each item of the PTG, over half the sample reported at least a moderate positive change.

MULTIVARIABLE ANALYSES

In the multivariable model including all participants, non-Hispanic whites had significantly lower PTG scores and compared to Hispanics (OR = 0.25, 95% CI: 0.13–0.45). The probability of falling into the highest category of PTG was 37% (95% CI: 28%–45%) among Hispanics, compared to 14% for non-Hispanic whites (95% CI: 8%–21%) and 23% for Other (95% CI: 13%–36%) (Figure 1). RSA was also significantly associated with PTG as either a linear (OR_{linear term} = 1.99, 95% CI: 1.12–3.53) or quadratic (i.e., curvilinear, inverted U) term (OR_{quadratic term} = 0.84, 95% CI: 0.73–0.97); the probability of reporting a highest quartile PTG score was 21% (95% CI: 13%–31%) for those who never attended religious services or

didn't know, 30% (95% CI: 22%–37%) for those who attended every few years, 34% (95% CI: 24%–43%) for those who attended several times a year, 30% (95% CI: 23%–38%) for those who attended 2–3 times a month, and 22% (95% CI: 13%–33%) for those who attended at least once a week (Figure 2).

In the multivariable model restricted to Hispanics, Hispanic and Anglo acculturation were each positively associated with PTG ($OR_{\text{Hispanic}}=1.96$, 95% CI: 1.37–2.81; $OR_{\text{Anglo}}=3.07$, 95% CI: 1.52–6.20) (Figures 3a&b), as was the interaction of those terms when added to the model ($OR=2.51$, 95% CI: 1.20–5.26). To more clearly illustrate the interaction of Hispanic and Anglo cultural orientation (i.e. the bi-dimensional nature of acculturation) and its relationship with PTG, the estimated probability of falling into the highest category of PTG was calculated for an individual scoring low on both acculturation subscales, high on both, or high on one and low on the other (Figure 3c). RSA was not significantly associated with PTG in the model among Hispanics only.

DISCUSSION

The majority of CCS reported at least moderate levels of growth as a result of their cancer experience. This finding is consistent with prior work among less ethnically diverse CCS²¹³. PTG was more commonly reported among Hispanics (vs. non-Hispanic whites), which is also consistent with previous research²⁹. This difference was not confounded by age, gender, treatment intensity, or RSA. These differences may be associated with protective cultural aspects, such as the interdependency of family members, which is a prominent source of social support among Latinos³⁰.

Among Hispanics, both Anglo and Hispanic orientation were significantly positively associated with PTG (while estimated PTG was greatest for those with high orientation to both cultures, estimated PTG for an individual scoring high on orientation to just one culture was still greater than an individual scoring low on both). Previously, Arpa Wong and colleagues found Anglo-oriented Hispanics reported significantly lower PTG, although this was in comparison to non-Hispanic whites, and only using language spoken at home as the acculturation indicator¹³. Our finding could indicate that having a stronger cultural identity is of greater importance in promoting successful psychosocial adaptation after childhood cancer than which particular culture one identifies with. That is, Hispanic CCS with lower levels of Hispanic *and* Anglo cultural identification may be less likely to experience positive growth following cancer. Having a strong sense of ethnic identity has been associated with self-efficacy and positive coping, feelings of belonging, and is thought to be protective of adverse mental health functioning³¹, which may support the development of PTG. Previous work by Berry identified distinct strategies that contribute to individuals' acculturative typologies such that they may assimilate (adopt the dominant culture and distance from the culture of origin), separate (the opposite of assimilate), integrate (embrace both cultures) or be marginalized (lose all cultural affiliation)¹⁰. Though this method of categorization has been debated, various studies have verified the existence of these categories in unique samples and have found that those who integrate tend to have more positive health outcomes such as increased mental health, self-esteem and coping-efficacy²⁵, supporting our findings. Future research should examine other culturally informed beliefs such as support

seeking and perceptions of disease (e.g., fatalism) which could also impact growth and wellbeing in the aftermath of a traumatic health event ²⁹.

Religiosity is commonly beneficial in times of distress, likely because of the sense of meaning and hope offered to those who believe in a higher power ³². However, our findings indicate that one aspect of religiosity, RSA, had an inverse-U relationship with PTG, with the highest PTG scores at moderate levels. Relevant characteristics previously associated with greater PTG include openness to religious change ³³ and deliberate reflection ³⁴. Thus, a potential explanation for decreased PTG among those with the highest levels/lowest levels of RSA could be cognitive rigidity ³⁵, which may inhibit openness and the willingness to contemplate one's experience that is needed for the development of PTG ^{33,34}. Moreover, the participants who spent the most time in religious services (and thus in the context of a like-minded community) may have employed more negative religious coping, which may be characterized by an ominous view of the world, interpreting cancer as a punishment from God, and/or interpersonal religious discontent ³⁶. Negative religious coping is associated with psychological distress ³⁷, which is negatively associated with PTG among CCS ³⁸. However, these potential explanations are speculative and may differ from previous studies due to differences in measurement. Studies with more detailed assessments of religiosity and related interpretations of negative life events are needed, including measures of intrinsic versus extrinsic religiosity, which have been shown to differentially impact health outcomes ³⁹.

While previous interventions have primarily targeted the reduction of maladaptive responses towards the cancer experience, emerging interventions have begun to address the cultivation of resiliency and positive adaptation ⁴⁰. PTG has been associated with physical health as well as quality of life among cancer patients ⁴¹, and may be an important target for supporting the health and wellbeing of CCS. Elucidating potential facilitators and inhibitors of PTG may help identify CCS in greatest need of support services. The associations between PTG and the ethnicity and cultural factors in this study suggest demographic differences in resilience, consistent with previous findings ^{13,24}. Future research is needed to examine specific cultural constructs (e.g., fatalism, familism) that can facilitate the development of PTG.

Supporting the development of PTG can include interventions that incorporate positive aspects of religious coping for CCS who identify religion as an important part of their lives. Specifically, interventions may aim to promote a sense of meaning from the cancer experience by encouraging survivors to draw from the meaning derived from their faith ⁴². A Meaning-Making intervention (MMi), designed to facilitate the search for meaning following a cancer diagnosis, has been tested in a randomized controlled study among ovarian cancer patients showing an improved sense of meaning, and a trend toward greater existential wellbeing in the intervention group ⁴³. Similar interventions may be useful for targeting facilitators of PTG among adolescent and young adult CCS. Other components of positive religious coping that may be modifiable intervention targets include seeking spiritual support or using religious or spiritual practices such as prayer to manage stress ^{42,44}.

This study has several limitations. The PTG scale used in this study did not capture negative change, only allowing for a participant to indicate "no change" at a minimum, and may not have captured the full range of experiences. However, the answer format used in this study

has been used previously when studying PTG among CCS⁴. The 50% response rate may also be a limiting factor with regard to the representativeness of the CCS population in Los Angeles County. While comparisons of demographic factors between responders and non-responders indicated that only gender differed significantly between the groups, selection bias may still pose a threat to external validity. Additionally, RSA captures just one aspect of religiosity and does not represent the psychological, cognitive, or emotional factors associated with religion⁴⁵. More comprehensive scales should explore associations with religiosity as a whole, including other dimensions such as religious views and impact of religious beliefs on the self⁴⁶. Spirituality, another construct distinct from RSA and religiosity, may also be uniquely associated with PTG and should also be examined in future studies. The Anglo orientation subscale had low internal consistency in this sample, so results should be interpreted with caution. Moreover, the acculturation findings may not generalize to non-Hispanic white CCS given that the scale used in the present study was specific to Hispanics. Finally, the cross-sectional nature of this study precludes causal inference.

CONCLUSION

The majority of CCS in this study reported experiencing PTG following their cancer experience. Among Hispanics, greater orientation toward either the Hispanic or Anglo culture was positively associated with PTG, a novel finding among this population suggesting that Hispanic CCS who do not exhibit strong orientation toward any/either culture are less likely to report PTG and may benefit from more targeted efforts to promote psychosocial adaptation in the aftermath of cancer. Contrary to previous studies, a curvilinear relationship was found between RSA and PTG, which suggests that moderate levels of church attendance (vs. high or low) may allow for the highest reporting of PTG. Longitudinal studies are needed to explore causality as well as mechanisms between these factors and PTG among CCS, with more detailed assessments of cultural identity and religious/spiritual beliefs/practices. Improved understanding of these potential facilitators of PTG can inform interventions aimed at improving the survivorship experience of CCS.

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Figure 1.
Estimated probability of reporting highest PTG scores, by ethnicity and religiosity

Figure 2.
Estimated probability of reporting highest PTG scores, by acculturation subscale score

Figure 3.
Estimated probability of reporting highest PTG scores, by acculturation

Table 1.

Participant characteristics

	N (%)	Mean PTG (SD)
Gender		
Male	116 (49.4)	37.7 (8.5)
Female	119 (50.6)	38.7 (7.5)
Ethnicity		
Hispanic	132(56.2)	39.9 (7.7)
White	62(26.3)	35.3 (8.1)
Other ^a	41(17.5)	38.0 (7.5)
Treatment intensity		
Least	22 (9.4)	35.9 (9.5)
Moderate	77 (32.9)	38.4 (8.9)
Very	105 (44.9)	38.7 (7.3)
Most	30 (12.8)	38.3 (7.0)
Religious service attendance		
Never/don't know	43(18.4)	37.9(7.7)
Every few years	30(12.8)	39.8(8.0)
Several times a year	68(29.1)	39.2(8.1)
2–3 times p/month	33(14.1)	38.3(6.8)
At least once p/week	60(25.6)	36.7(8.7)
	Mean (SD)	Range
Age at survey	19.8(2.8)	15–25
Age at diagnosis	12.3(3.0)	5–19
Hispanic orientation ^b	19.01(6.7)	6–30
Anglo orientation ^c	29.3(3.8)	16–35

^aOther=American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Pacific Islander;

^bMean of 6 items;

^cMean of 7 items