Role of Peer Support in Posttraumatic Growth Among Adolescent and Young Adult (AYA) Patients and Survivors with Pediatric and AYA Cancer

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Research Article

Keywords: posttraumatic growth, adolescent and young adult, cancer, peer support

Posted Date: December 29th, 2021

DOI: <https://doi.org/10.21203/rs.3.rs-1059986/v1>

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Abstract

Purpose

Adolescents and young adults (AYA) who undergo cancer treatment sometimes report posttraumatic growth (PTG) and experience posttraumatic stress symptoms (PTSS). Although the importance of peer support has been demonstrated, its association with PTG, especially in the five, distinct domains of PTG, needs to be investigated further in AYA cancer survivors. The present study examined the role of demographics, peer support, and PTSS in PTG among AYA cancer patients and survivors.

Methods

The present, multicenter, cross-sectional, prospective, web-based study enrolled AYA cancer patients and survivors (median age 28 years). Of 549 AYA patients recruited, 212 patients from 11 cancer centers and 12 cancer patient communities agreed to participate by completing a self-reported measure of PTG (PTGIX-J) and providing information about their diagnosis, treatment, peer support (affiliation with an AYA patient community or friendship with other AYA cancer patients), social status, and PTSS. Multiple regression analysis was used to identify significant correlates in the total score and five PTG domains.

Results

In general, PTG was positively associated with male sex, years since diagnosis, having a confidant, and friendship with other AYA cancer patients. PTG was not significantly related to age, age at diagnosis, affiliation to an AYA patient community or PTSS. Friendship with other AYA cancer patients was positively associated with all five PTG subscales. PTSS was not associated with PTG but was associated with a subscale of “appreciation of life”. For the five subscale scores, “belonging to a religion” was positively associated with “spiritual change,” and “having a confidant” and “a good relationship with siblings” were positively associated with “appreciation of life.”

Conclusion

“Having a confidant” and “friendship with other AYA cancer patients” was positively associated with PTG. Psychosocial interventions mobilizing peer support can potentially contribute to promoting PTG in AYA cancer patients.

Introduction

Adolescent and young adulthood are challenging developmental phases characterized by physical, emotional, cognitive, and social transitions [1]. Adolescent and young adult (AYA) patients and survivors have important and complex, age-related developmental tasks, such as developing self-identity, becoming independent, completing education, pursuing gainful employment, having a relationship, dating, and having children [2, 3]. A cancer diagnosis, its treatment, and its late effects complicate these normative

developmental challenges and can negatively affect the physical and psychological functioning of AYAs [4, 5].

Symptoms of posttraumatic stress (PTSS) are reported by pediatric and AYA cancer patients and survivors. Kwak et al. reported that 39% and 44% of AYAs aged 14-39 years at diagnosis reported moderate to severe levels of PTSS at six and 12 months after diagnosis, respectively [6]. On the other hand, perhaps because of the disruption of worldviews and challenges to their core beliefs, many pediatric and AYA patients and survivors report psychological growth and positive change while dealing with cancer, a phenomenon known as posttraumatic growth (PTG) [7, 8]. PTG refers to positive psychological change occurring as a result of a struggle with a major life crises or traumatic events and can be defined operationally as having five domains. These encompass one's ability to relate to others after the traumatic experience; a sense of new possibilities; reinforced feelings of personal strength and resilience; the experience of spiritual and existential change; and an increased appreciation of life [9].

Previous studies have reported a correlation between aspects of PTSS and PTG. PTG in breast cancer patients was positively associated with a perceived threat to life, prior discussion of breast cancer, income, and time since diagnosis [10]. In AYA cancer patients, Husson et al. reported that female sex, younger age, and chemotherapy were positively associated with PTG [11].

Recently, peer support is increasingly being advocated for inclusion in patient treatment and care [12], but little is known about its effectiveness in the context of AYA cancer. Some studies have reported unmet needs in peer support for AYA cancer patients [13]. In Japan before the current COVID-19 pandemic, AYA patient communities provided opportunities for face-to-face exchanges between AYA cancer patients. We herein hypothesized that peer support is positively associated with PTG and conducted the present, multicentric, cross-sectional, prospective, questionnaire-based study to investigate its role in PTG and to identify the factors associated with the PTG experiences of AYA cancer survivors and patients in Japan.

Methods

Patients selection and questionnaire distribution

The present study was conducted using a cross-sectional research design with an anonymous, web-based survey that included a series of open and closed questions. An online questionnaire was first distributed to the attending physicians at the 11 participating cancer centers and the directors of 12 cancer patient communities across Japan between May 2018 to May 2019. The physicians and the heads then distributed the survey weblink to their patients or members to recruit participants.

The eligibility criteria included age 15-39 years, a diagnosis of any invasive cancer, and the ability to read and understand Japanese. Institutional Review Board approval was obtained from each participating center. Web-based informed consent was obtained from all the participants. Patients were excluded if they did not provide online consent or did not click the submit button at the end of the survey.

PTG

Posttraumatic growth was assessed using the Extended Version of the Posttraumatic Growth Inventory-Japanese (PTGI-X-J) [14]. Twenty-five items were assessed on a six-point Likert scale ranging from 0 (no change at all) to 5 (very great change) for five subscales (Factor I to V): “relating to others” (seven items), “new possibilities” (five items), “personal strength” (four items), “spiritual change” (six items), and “appreciation of life” (three items). The participants were instructed to think about their cancer diagnosis as a reference point when responding to the items. The mean score for each of the five subscales was derived by summing the response values and dividing by the number of items per subscale. Higher scores indicated greater growth. The mean score for all 25 PTGI-X-J items was also calculated. The scale demonstrated high internal consistency (Cronbach’s $\alpha=0.94$).

PTSS

Post-traumatic stress symptoms were measured using the Japanese version of the Impact of Event Scale-Revised (IES-R) developed by Weiss and Marmar [15], a self-reported tool containing 22 items designed to assess current subjective distress related to a traumatic life event [15]. Although three subscale scores (intrusion, hyperarousal, and avoidance) were able to be obtained, the decision was made to use the overall mean score after mistakenly omitting one item and collecting 21 items in total. The response format was a five-point Likert scale of agreement ranging from 0 = not at all to 4 = extremely. The scale demonstrated high internal consistency (Cronbach’s α 0.92) [16]. In the present study, the Cronbach α was also excellent at 0.92.

Statistical methods

The primary outcome in this study was PTG, indicated by the PTGI-X-J total and five subscale scores. To explain variance in the PTGI-X-J scores, several predictors were selected: (1) age, (2) sex, (3) age at diagnosis, (4) years since diagnosis, (5) religiosity, (6) affiliation with an AYA patient community, (7) friendship with other AYA cancer patients, (8) PTSS, and (9) other illness/treatment-related factors. Univariate and multivariable linear regression analyses were used to identify variables significantly associated with the total score and five subscale scores of the PTGI-X-J. The initial multivariable regression model was constructed by including variables that were significantly related to PTG on univariate analyses at $p \leq .20$. Stepwise backward elimination was then used to identify correlates of PTG at $p \leq .05$ in the final multivariable model. Additional regression analyses were conducted for patients who were affiliated with an AYA patient community and separately for those who were not to further examine the pattern of PTG predictor variables. All the data were analyzed using Stata, version 16.0 (StataCorp).

Results

Out of the 549 patients who were initially recruited, 212 respondents (38.6%) qualified for enrollment and completed the questionnaire. Table 1 summarizes their demographic and clinical characteristics; 136

(64.2%) patients were female, the median age of the entire cohort was 28 years (IQR: 22.5-34.0 years), and 146 (68.9%) received their diagnosis in adolescence or young adulthood. The patients had a variety of cancers, most of which had already been treated (80.2%). The median years since diagnosis was six (IQR 2-12) years. The IES-R score was 0.74 (SD=0.66), indicating a lower level of PTSS. PTSS was associated with years since diagnosis, unemployed status, and symptoms of late effects. PTSS was, however, not associated with age, age at diagnosis, friendship with other AYA cancer patients or affiliation to an AYA patient community. PTS was only associated with one of the five PTG subscales, “appreciation of life.”

Posttraumatic growth

The overall mean PTGI-X-J score, Factor II (“new possibilities”) score, and factor V (“appreciation of life”) score for the entire cohort were 2.98 (SD=1.09), 3.20 (SD=1.37), and 3.67 (SD=1.23), respectively, and ranged from 0 to 5. Among the patients, those with pediatric or AYA cancer reported a slightly lower level of change across all the PTGI-X-J items (mean score 2.74) but reported a higher level of positive change in Factors II (new possibilities, mean = 3.02) and V (“appreciation of life,” mean = 3.49).

PTG correlates

Univariate analysis revealed that men reported significantly higher PTG than women ($P=0.031$). PTG was positively associated with years since diagnosis, having a confidant, and friendship with other AYA cancer patients but did not differ significantly by age, age at diagnosis, treatment status, experience of relapse, late effects, religiosity or affiliation with an AYA patient community (Table 1).

In line with the univariate analysis, multivariable analysis of overall PTG found a positive relationship with male sex, years since diagnosis, good communication with others, and friendship with other AYA cancer patients (Table 2). Friendship with other AYA cancer patients was positively associated with all five subscales of PTG. In addition, Factor I (“relating to others”) was positively associated with years since diagnosis and having a confidant. Factor II (“new possibilities”) was positively associated with being male and having a confidant. Factor III (“personal possibilities”) was not associated significantly with any predictor other than having a friendship with other AYA cancer patients. Factor IV (“spiritual change”) was positively associated with being male, years since diagnosis, and religiosity. Finally, Factor V (“appreciation for life”) was positively associated with having a sibling with whom they were able to discuss their situation and the IES-R score for PTSS (Table 2).

Comparison with and without an AYA patient community affiliation

Table 3 compares the PTGI-X-J scores between patients with and without an AYA patient community affiliation. Of the 212 AYAs, 107 were affiliated with an AYA patient community, and 105 were not. Multivariable analysis of the PTG score of AYA patients with no affiliation found a positive relationship with years since diagnosis ($p=0.011$), having a confidant (mean PTG: 2.70, $p=0.046$), and friendship with

other AYA cancer patients (mean PTG: 2.98, $p=0.001$). The PTG score of AYA patients with an affiliation, on the other hand, was positively associated with belonging to a religion (mean PTG: 3.51, $p=0.011$) and negatively associated with being affiliated with a patient community outside the AYA age group, i.e., a mostly adult group (mean PTG: 2.50, $p=0.015$).

Discussion

The present study indicated that friendship with other AYA cancer patients was most consistently associated with PTG, regardless of the PTG subscales. The present study is the first study to demonstrate the importance of friendship among AYA cancer patients and survivors for PTG. It is widely known that friendships are particularly important for adolescents when coping with adversity, including feelings of loneliness, isolation, and identity challenges. The current study provided further evidence of the critical role that the friendship may play in adolescent mental health.

Our study demonstrated that male sex, years since diagnosis, confidence when with others, and friendship with other AYA cancer patients were positively associated with PTG. Husson et al. reported that female sex, younger age, and chemotherapy were more prominent factors in the high PTG group among AYA cancer patients [10]. Shand et al. also reported that women experienced higher levels of PTG than men in their systematic review of oncology patients [17]. Some studies have suggested that female patients are more emotionally focused in their coping strategies and may therefore be more capable than men in deriving a positive meaning from their cancer experience [20, 21]. In the present study, however, male AYA survivors were associated with a higher level of PTG than their female counterparts, especially in the domains of “new possibilities” and “spiritual change.” As shown in a PTG study conducted with Japanese participants, sex was not a prominent factor unlike in PTG studies conducted in the West [24]. This discrepancy may reflect the cultural characteristics of Japanese AYA cancer patients but may also be due to the unequal sample size of the male and female participants in this study. Further research is required to verify our findings.

In terms of affiliation with an AYA patient community, the PTG of subjects with no affiliation was positively associated with friendship with AYA cancer patients and having a confidant. On the other hand, the PTG of patients with an AYA patient community affiliation was associated with belonging to a religion rather than with friendship with other AYA cancer patients. These results indicated that, for those who were not affiliated with a patient community group, peer support and having a confidant were important factors in promoting PTG. In patients with a community affiliation, belonging to a religion was apparently the driving factor in promoting PTG. Belonging to a religion was also positively associated with the spiritual change domain of PTG. A previous study indicated that PTG among cancer patients was positively associated with belonging to a religion [17]. Spiritual belief provides a framework within which traumatic events can be interpreted, thus facilitating growth and enhancing positivity [18]. A systematic review found that six studies reported a positive association between religious coping and PTG [19]. Since only 10% of AYAs belonged to a religion in our study, the sample size may have been insufficient for any clear conclusions to be drawn, but at any rate religiosity was found to have an additional effect on

PTG in AYAs with an affiliation with a patient community. Further research is needed to explore the mechanisms by which religious membership, particularly in Japanese culture, may influence PTG among patients with cancer.

Affiliation with a non-AYA cancer patient community was negatively associated with PTG. One potential implication of this finding is that the age-related disparities in social background and values between AYA and adults patients may have hindered PTG. As well, belonging to multiple patient communities may indicate that the patients are seeking support because of their stronger sense of isolation or loneliness and psychological hardship, which in turn may lead to a lower level of perceived PTG. Overall, this finding indicates that not only the experience of having cancer or belonging to a patient support network but also belonging to a peer group coupled with friendship are critical for personal growth in AYA cancer patients and survivors.

The breakdown of the individual PTG domains reveals some noteworthy differences. Years since diagnosis was associated with “relating to others” and “spiritual change.” Danhauer et al. reported in their longitudinal study of PTG in patients with leukemia that PTG increased with the passage of time after transplantation [19], i.e., survivors and patients were able to make sense of their condition and develop compassion and new friendships with time. Future research should aim to clarify how “years since diagnosis” is associated with two of the five PTG domains.

The current study indicated that having a sibling with whom patients were able to discuss their situation was positively associated with “appreciation of life.” Shand et al. reported that social support was positively associated with PTG [17]. Social support from family may promote the construction of meaning and growth by facilitating the cognitive processing of experience.

Our study showed that PTG did not linearly correlate with PTSS. Only “appreciation of life” was positively associated with PTSS. Zebrack et al. also reported that PTG did not interact with PTSS with the exception of “new possibility of life.” Moreover, “personal growth” was positively associated with the re-experiencing subscale of the Posttraumatic Stress Diagnostic Scale [22]. It may be the case that PTS and PTG consist of different processes which may co-exist but are largely independent [23] or they may have a curvilinear relationship.

Clinical implications

The results of this study suggest that it is necessary to provide opportunities for interaction with the other AYA cancer patients both inside and outside the hospital to improve patients’ quality of life by promoting PTG.

Study Limitation

Our study has some limitations. First, it was more likely to be cofounded by subsequent life events because it included participants many years after their treatment as well as a heterogeneous mix of patients who were on and off therapy. Second, the small sample size might have led to underestimating

the influence of various factors in univariate analysis while also precluding the use of multivariate analysis. Third, one item on the IES-R total score was mistakenly omitted. In view of these limitations, future studies are needed to verify our finding that peer support has positive effects on PTG among AYA cancer survivors and patients.

Conclusion

Good communication with others and friendship with other AYA cancer patients were positively associated with PTG but not with PTS. Psychosocial intervention facilitating peer support among AYA cancer patients has the potential to improve patients' quality of life by promoting PTG.

Declarations

Acknowledgements

We thank Mr. James Robert Valera for his assistance with editing this manuscript.

Funding: This study was supported in part by the Foundation for the Promotion of Cancer Research in Japan.

Conflicts of interest/Competing interests: The authors have stated explicitly that there are no conflicts of interest in connection with this article.

Availability of data and material: The data that support the findings of this study are available from the corresponding author upon reasonable request.

Code availability: Not applicable

Authors' contributions: All of the authors contributed equally to the conceptualization of the manuscript; Motohiro Matsui drafted the manuscript. All of the authors provided critical appraisal of the manuscript and approve of its submission.

Ethics approval: Ethics approval was obtained from the Institutional Review Board of the Tokyo Metropolitan Children's Medical Center (number H29b-123). Informed consent was obtained from all participants prior to their participation in the study. This research conforms to the Declaration of Helsinki.

Consent to participate: Web-based informed consent was obtained from all the participants.

Consent for publication: Not applicable

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Tables

TABLE 1. Sample characteristics and relationship to post-traumatic growth

	N (%) or median variable (IQR)	Mean PTG (SD)	P value
Age, years	28 (22.5-34)		0.652*
Sex			0.031**
Female	136 (64.1)	2.62 (1.05)	
Male	76 (35.9)	2.96 (1.14)	
Age at diagnosis, y			
0-14 (pediatric)	66 (31.1)		
15-39 (AYA)	146 (68.9)		
Type of cancer			
Leukemia	58 (27.4)		
Breast carcinoma	39 (18.4)		
Lymphoma	31 (14.6)		
Brain tumor	12 (5.7)		
Cervical cancer	9 (4.3)		
Treatment status			0.869
Off treatment	170 (80.2)	2.75 (1.09)	
On treatment	42 (19.8)	2.72 (1.09)	
Years since diagnosis	6 (2-12)		0.019
Experience of relapse			0.338
No	141 (82.9)	2.79 (1.11)	
Yes	29 (17.1)	2.57 (1.02)	
Treatment			
Radiation			
No	167 (78.8)	2.78 (1.10)	0.354
Yes	45 (21.2)	2.61 (1.08)	
Cranial radiation			
No	193 (78.8)	2.79 (1.09)	0.038

Yes	19 (21.2)	2.25 (1.04)	
HSCT			
No	179 (84.4)	2.74 (1.08)	0.978
Yes	33 (15.6)	2.75 (1.18)	
Surgery			
No	83 (39.2)	2.80 (1.03)	0.547
Yes	129 (60.8)	2.71 (1.13)	
Late effect			0.710
No	151 (71.2)	2.76 (1.10)	
Yes	52 (24.5)	2.69 (1.08)	
Good communication with others			0.017
No			
Yes	19 (9.0)	2.17 (1.27)	
	193 (91.0)	2.80 (1.06)	
Friendship with other AYA cancer patients			0.001
No			
Yes	92 (43.4)	2.47 (1.20)	
	120 (56.6)	2.95 (0.96)	
Religious affiliation			0.232
No	167 (78.8)	2.72 (1.05)	
Yes	22 (10.4)	3.01 (1.29)	
Affiliation with adult cancer patient community			0.976
No	181 (85.4)	2.74 (1.06)	
Yes	31 (14.6)	2.75 (1.26))	
Affiliation with AYA cancer patient community			0.129
No			
Yes	130 (61.3)	2.65 (1.14)	
	82 (38.7)	2.89 (1.01)	
Diagnosis of infertility			0.421

No	107 (50.4)	2.77 (1.06)	
Yes	49 (23.1)	2.62 (1.05)	
Married			0.385
No	120 (56.6)	2.68 (1.09)	
Yes	36 (17.0)	2.85 (0.93)	
IES-R			0.706

* Pearson R for continuous variables, **ANOVA for categorical variables. Bold numbers indicate significant P value.

Abbreviations: IQR, interquartile range; HSCT, hematopoietic stem cell transplantation

TABLE 2. Multivariable regression analysis of post-traumatic growth

Variables	Over all Estimate (p)	<i>Relating to others</i>	<i>New possibilities</i>	<i>Personal strength</i>	<i>Spiritual change</i>	<i>Appreciation of life</i>
Female sex	-0.36 (0.016)		-0.45 (0.015)		-0.41 (0.011)	
Years since diagnosis	-0.03 (0.001)	-0.03 (0.005)			-0.03 (0.004)	-0.01 (0.404)
Experience of relapse				-0.41 (0.108)		
Brain tumor	-0.24 (0.549)	-0.57 (0.192)				
Cranial radiation	-0.42 (0.193)	-0.38 (0.279)				
Religious affiliation					0.55 (0.029)	
Having a confidant	0.59 (0.019)	0.42 (0.011)	0.67 (0.041)	0.33 (0.374)		
Having a good relationship with siblings						0.52 (0.004)
Affiliation to AYA patient community			0.31 (0.162)			
Friendship with other AYA cancer patients	0.55 (<0.001)	0.65 (0.022)	0.52 (0.011)	0.64 (0.001)	0.39 (0.021)	0.35 (0.046)
IES-R						0.02 (0.009)

TABLE 3. Univariable and multivariable regression analysis of post-traumatic growth in the group of affiliation with AYAcancer patient community and the group without.

	No Affiliation with AYAcancer patient community			Affiliation with AYAcancer patient community		
	N=105			N=107		
	Mean PTG (SD)	univariable regression analysis	Multivariable regression analysis	Mean PTG (SD)	univariable regression analysis (P value)	Multivariable regression analysis
Age, years		0.863*			0.151*	
Sex		0.217**			0.054**	
Female	2.54 (1.16)			3.09 (1.05)		
Male	2.83 (1.22)			2.71 (0.94)		
Age at diagnosis, y		0.278**			0.793**	
0-14 (pediatric)	2.50 (1.22)			2.77 (1.26)		
15-39 (AYA)	2.76 (1.16)			2.85 (0.92)		
Brain tumor		0.030**	0.150		0.229**	
No	2.68 (1.17)			2.87 (0.99)		
Yes	1.18 (0.54)			2.46 (1.00)		
Treatment status		0.739**			0.990**	
Off treatment	2.66 (1.17)			2.84 (0.94)		
On treatment	2.56 (1.28)			2.84 (1.01)		
Years since diagnosis		0.038*	0.011		0.492*	
Experience of relapse		0.845**			0.083**	
No	2.65 (1.18)			2.93 (1.03)		
Yes	2.72 (1.20)			2.41 (0.80)		
Treatment						

Radiation		0.493**		0.172**
No	2.72 (1.24)		2.94 (1.02)	
Yes	2.56 (1.13)	0.015**	2.68 (0.93)	0.337**
Cranial radiation				
No	2.71 (1.18)		2.87 (0.98)	
Yes		0.551**		0.764**
HSCT	1.51 (0.57)		2.59 (1.04)	
No				
Yes	2.61 (1.17)	0.559**	2.85 (0.98)	0.083**
Surgery				
No	2.77 (1.24)		2.77 (1.06)	
Yes				
	2.56 (1.04)		3.05 (0.97)	
	2.72 (1.28)		2.71 (0.99)	
Late effect		0.614**		0.908**
No	2.67 (1.15)		2.83 (0.79)	
Yes	2.54 (1.28)		2.85 (0.79)	
Good communication with others		0.048**	0.046	0.075**
No	1.72 (1.32)		2.38 (1.24)	
Yes	2.70 (1.16)		2.90 (0.94)	
Friendship with other AYA cancer patients		0.024**	0.001	0.066**
No	2.45 (1.24)		2.56 (1.11)	
Yes	2.98 (1.02)		2.94 (0.93)	

Religious affiliation		0.790**		0.045**	0.015
No	2.63 (1.16)		2.80 (0.94)		
Yes	2.72 (1.33)		3.51 (1.11)		
Affiliation with adult cancer patient community		0.216**		0.028**	0.011
No	2.60 (1.17)		2.97 (0.85)		
Yes	3.09 (1.33)		2.50 (1.25)		
Diagnosis of infertility		0.134**		0.158**	
No	2.52 (1.20)		2.95 (0.91)		
Yes	2.61 (1.15)		2.63 (0.95)		
Married		0.234**		0.794**	
No	2.44 (1.25)		2.85 (0.94)		
Yes	2.81 (0.91)		2.92 (0.92)		
IES-R		0.319*		0.398*	

* Pearson R for continuous variables, **ANOVA for categorical variables. Bold numbers indicate significant P value.

Abbreviations: IQR, interquartile range; HSCT, hematopoietic stem cell transplantation