

Post-Traumatic Growth among Family Caregivers of Cancer Patients and Its Association with Social Support and Hope

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ABSTRACT

Background: Cancer not only is a traumatic experience for the patients, but also can affect the family caregivers. Post-traumatic growth (PTG) refers to positive psychological changes experienced by people as a result of a struggle in dealing with traumatic events in life. Both the patients and their caregivers may experience PTG. The present study aimed to assess the extent of PTG in caregivers of patients with gastrointestinal cancer and to examine the relationship between the PTG dimensions and both the social support (SS) and hope.

Methods: The present descriptive correlational study was conducted during May-August 2018 in Shiraz, Iran. The target population included 112 caregivers who visited hospitals affiliated to Shiraz University of Medical Sciences, Shiraz, Iran. Data collection instruments included a demographic information form, post-traumatic growth inventory, social support appraisals scale, and Miller hope scale. The data were analyzed using the SPSS software (version 23.0). $P < 0.05$ was considered statistically significant.

Results: The mean score for PTG, hope, and SS was 75.41 ± 16.49 , 190.95 ± 24.20 , and 89.10 ± 12.84 , respectively. A significant positive correlation was found between PTG and both SS ($P < 0.001$, $r = 0.59$) and hope ($P < 0.001$, $r = 0.70$). The results of the multiple regression analysis showed a significant relationship between PTG, SS, and hope ($P < 0.001$). Hope had a higher effect on PTG ($\beta = 0.62$) compared to SS ($\beta = 0.27$).

Conclusion: The results showed a good level of PTG among the caregivers and the experience of stressful situations positively affected their psychological condition. The positive change was associated with the perceived SS and hope.

KEYWORDS: Cancer, Caregivers, Hope, Post-traumatic growth, Social support

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INTRODUCTION

Cancer not only is a traumatic experience for the patients, but also can affect the mental health of family caregivers. Both the emotional involvement and financial burden expose these caregivers to various physical and psychological challenges.¹ Anxiety and depression are a common experience and are influenced by factors directly related to the patient (age, the extent of discomfort, and functional, emotional and physical status) as well as factors related to the disease symptoms and the caregivers' level of experience.^{2,3} The interplay between cancer patients and caregivers in terms of negative emotions, low mood, and signs of depression is well-documented.⁴ However, positive emotions and behavior may also emerge from such traumatic experience.

The psychological process of rumination occurs after exposure to a traumatic event. It involves search for meaning in a disturbing event and regulates the associated emotions.⁵ This process is called post-traumatic growth (PTG). The theory of PTG refers to positive psychological changes experienced by people following a struggle in dealing with traumatic events and dilemmas in life. It is shown that after a trauma, not only people can transform and return to their usual function and performance, but also it can result in personal growth.⁶ PTG results from a struggle to deal with a major crisis in life and the search to find meaning in that experience.⁷ PTG includes some coping strategies, leads to adaptation to the traumatic event and creates a more positive perspective of the world.⁸ It requires reflection on the experiences and the struggle to make sense of and to cope with that trauma.⁹

It generates a greater sense of personal strength, values, psychological maturity, and empathy. Additionally, it improves interpersonal relationships, participation in social activities, and planning for the future.¹⁰

Some studies have shown a positive correlation between PTG and resilience, resulting in improved social performance and

the ability to overcome problems following the exposure to severe stress and risk factors.^{11,12} PTG is also related to the quality of life (QoL) and plays a protective role. However, lower levels of PTG have a negative impact on mood and QoL.¹³

Caregivers are also exposed to trauma, as a side effect of caring for cancer patients, and may experience PTG.¹³ PTG in caregivers could be in the form feeling of intrinsic rewards, experience of a positive self-image and social-image through helping others, an enhanced sense of purpose, and a new appreciation for life.⁹ To date, the majority of studies have focused on PTG in cancer patients¹⁴⁻¹⁷ and there are only a few studies, though contradictory, on its effect on caregivers. A previous study reported that an equal level of PTG was experienced by both prostate cancer patients and their caregivers,¹⁸ whereas, in other studies, a higher effect on PTG (all or some aspects) in either the patients or caregivers was reported.^{13,19}

The factors affecting PTG are the dimensions of social support (SS) and hope. Perceived SS refers to various forms of assistance (emotional, instrumental, financial) provided by a network of people (family, friends, neighbors, general public) in times of need.²⁰ Additionally, Hope means being dominated by life, feeling of power and discretion, and sense of collective purpose and focus on higher goals.²¹ The relationship between PTG and hope has been studied in cancer patients¹⁶ as well as the parents of children with cancer.²² However, to the best of our knowledge, no reports have been published on other types of caregivers. In addition, only a few studies have been conducted^{15,17,23} on the dimensions of the perceived SS; for example, a study²³ briefly has indicated that the perceived SS is a strong factor affecting PTG. However, none of the above-mentioned studies examined the relationship between the perceived SS and PTG in caregivers of cancer patients. Last but not the least, the effect of culture and belief on PTG should also be studied across different cultural and

social groups.

Considering the above points, with a specific focus on caregivers, there was a clear need to examine the effect of perceived SS and hope on the dimensions of PTG. Hence, the present study aimed to assess the extent of PTG in the family caregivers of patients with gastrointestinal cancer and examine the relationship between the PTG dimensions and both the perceived SS and hope.

MATERIALS AND METHODS

As part of a larger research project, the present descriptive correlational study was conducted during May-August 2018 in Shiraz, Iran. The target population included family caregivers of patients with gastrointestinal cancer who visited the Amir Oncology Hospital, Mottahari Clinic, and Imam Reza Clinic, all being affiliated to Shiraz University of Medical Sciences, Shiraz, Iran. The sample size was estimated 112, based on a similar study,²⁴ using the following formula (considering $\alpha=0.05$ and $\beta=0.1$ with 15% attrition rate).

$$n = 3 + \frac{2(Z_{\alpha} + Z_{\beta})^2}{\left(\ln\left(\frac{1+\rho}{1-\rho}\right)\right)^2}$$

The inclusion criteria comprised acting as the principal caregiver, at least 6 months of caregiving experience with cancer patients, no diagnosis of cognitive or psychological disorders, and awareness of the patients' medical diagnosis. The exclusion criterion was partial completion of the questionnaires.

The data collection instruments included a demographic information form, post-traumatic growth inventory (PTGI), social support appraisals (SS-A) scale, and Miller hope scale (MHS). Demographic characteristics of the participants included sex, age, marital status, education level, occupation, the area of residence, relationship with the patient, and the frequency of caregiving.

PTGI is a 21-item self-report questionnaire developed and standardized by Tedeschi and Calhoun in 1996. The five dimensions of the

questionnaire include *new life possibilities, relating to others, appreciation of life, personal strength, and spiritual change*. The items of the questionnaire are answered on a 6-point Likert scale ranging from score 0 (I experienced no change) to score 5 (I experienced change to a high degree). The total test score ranges from 0 to 105 and higher scores on the PTGI indicate a greater degree of PTG. The psychometric properties of this tool were examined by factor analysis, concurrent validity, and discriminant validity. The internal consistency of the questionnaire was $\alpha=0.9$, and for the five dimensions it ranged from $\alpha=0.67$ to $\alpha=0.85$. Moreover, its test-retest correlation coefficient was 0.71.⁶

The reliability and validity of the Persian version of the questionnaire were examined by Heidarzadeh (2014), confirming the 5-factor structure of the PTGI. The reported internal consistency was $\alpha=0.87$, and for the five dimensions it ranged from $\alpha=0.57$ to $\alpha=0.77$. The test-retest correlation with a 30-day interval in 18 patients was $ICC=0.75$.²⁵ We also examined and confirmed the reliability of the questionnaire ($\alpha=0.92$).

The SS-A scale was developed by Vaux et al. (1986) based on Cobb's definition of social supports. The 23-item questionnaire includes three domains of family, friends, and others. The items of the questionnaire are answered using a 5-point Likert scale ranging from score 1 (very little) to score 5 (very much). The total test score ranges from 23 to 115.²⁶ The validity of the SS-A was assessed in terms of convergent and divergent validity with other subjective support measures, which was consistently quite good. The internal consistency of the scale and subscales was consistently very good across the samples.²⁶

The reliability of the Persian version of the questionnaire was confirmed in one study by Cronbach's alpha 0.77.²⁷ In the present study, the internal consistency was examined and the Cronbach's alpha coefficient equaled 0.88.

The MHS questionnaire was developed by Miller in 1988 to measure the level of

hope.²⁸ The 48-item self-report questionnaire includes the domains of hopefulness and desperation. The items of the questionnaire are answered using a 5-point Likert scale ranging from score 1 (totally disagree) to score 5 (totally agree). Note that 12 items in the questionnaire are in the form of a negative statement and the answers are reverse scored. The total test score ranges from 48 to 240. Content validity of the MHS was evaluated by 10 experts with expertise in hope (n=4) and measurement (n=6). Construct validity of this tool was established by correlating the MHS to the well-being and hope scales with $r=0.64$ to $r=0.82$. Moreover, divergent validity with the Hopelessness Scale was established ($r=0.54$). The reliability of the MHS was confirmed by test-retest ($r=0.82$) and Cronbach's alpha 0.93.²⁸ Concurrent validity of the Persian version of the hope questionnaires was assessed by measuring the correlations of the MHS with two other hope instruments ($P<0.001$).²⁹ Its reliability was confirmed in a study by Cronbach's alpha 0.91.³⁰ The reliability of this tool was confirmed in the present study ($\alpha=0.94$).

The demographic, PTGI, SS-A, and MHS questionnaires were thoroughly explained to the participants. Out of the 129 caregivers, 17 partially completed the questionnaires and were thus excluded from the analysis. The questionnaire of illiterate participants was filled out by the researcher, based on the input of the participants, following a clear explanation of each item.

The data were analyzed using the SPSS software (version 23.0). Descriptive and analytical data were analyzed using the Pearson correlation coefficient, independent sample t test, one-way analysis of variance, and multiple regression analysis. In the case of non-normal distribution, the equivalent non-parametric analysis was used. $P<0.05$ was considered statistically significant.

The study was approved by the Research Ethics Committee of Shiraz University of Medical Sciences, Shiraz, Iran (code: IR.SUMS.REC.1397.6). The participants were

personally informed about the goals of the research, methodology, and confidentiality of any disclosed information. They were assured that their participation had no effect on the treatment of and care for the patients. Written informed consent was obtained from all participants.

RESULTS

The mean age of the participants was 40.82 ± 12.85 years and the majority of them (67.9%) were aged 36-55 years. The participants were mainly employed 47 (42%) and had a university education 64 (57.2%). Married caregivers comprised 92 (82.1%) of the participants, out of whom 49 (43.8%) were the patient's spouse. A high proportion of the participants 44 (75%) lived in urban areas, and the frequency of caregiving (more than 3 times per week) was 69 (61.6%) (Table 1). The mean score for PTG, hope, and perceived SS was 75.41 ± 16.49 , 190.95 ± 24.20 , and 89.10 ± 12.84 , respectively. Among all demographic characteristics, the results only showed a significant difference in mean of PTG according to sex ($P=0.04$) and marital status ($P=0.04$) (Table 1).

The analysis of Pearson correlation coefficient showed a significant positive correlation between PTG and perceived SS ($P<0.001$, $r=0.55$). It indicated that the higher the perceived SS and its dimensions, the higher the score for PTG and its dimensions. Perceived SS had the highest correlation with the PTG dimensions: *relating to others* ($r=0.65$), *new possibilities* ($r=0.50$), and *personal strength* ($r=0.41$), whereas *spiritual change* ($r=0.35$) had the lowest correlation. On the other hand, PTG had the highest and lowest correlation with the dimensions of perceived SS: *family* ($r=0.505$) and *friends* ($r=0.45$), respectively (Table 2). In terms of the role of hope, the analysis of the Pearson correlation coefficient showed a significant correlation between hope and PTG ($P<0.001$, $r=0.70$); the higher the level of hope, the higher the PTG score. The dimensions of hope had the highest correlation with the

Table 1: PTG in caregivers with respect to demographic characteristics

Variables		N (%)	Mean±SD	P value
Sex	Male	56 (50)	78.50±12.77	0.04*
	Female	56 (50)	72.33±19.15	
Marital status	Single	20 (17.9)	75.00±14.27	0.04***
	Married	92 (82.1)	76.75±14.81	
Education level	Elementary	24 (21.4)	92.91±13.06	0.23**
	Diploma	24 (21.4)	71.66±14.63	
	University	64 (57.2)	75.21±18.06	
Occupation	Employed	47 (42)	74.36±15.03	0.38**
	Housewife	31 (27.7)	73.25±15.02	
	Unemployed	14 (12.5)	75.71±25.71	
	Retired	20 (17.8)	81.05±13.77	
Area of residence	Rural	28 (25)	79.75±12.76	0.10*
	Urban	84 (75)	73.97±17.39	
Relationship with the patient	Parent	5 (4.5)	79.60±9.37	0.15**
	Offspring	46 (41)	70.84±17.08	
	Spouse	49 (43.8)	78.30±17.52	
	Others	12 (10.7)	79.41±5.43	
Caregiving frequency	<3 days/week	43 (38.4)	77.26±14.04	0.76**
	>3 days/week	69 (61.6)	75.24±18.33	
Caregiver's helper	Parent	8 (7.1)	87.50±9.84	0.056**
	Offspring	41 (36.6)	78.39±16.84	
	Spouse	26 (23.2)	71.96±13.75	
	Family member	33 (29.5)	72.72±17.95	
	Others	4 (3.6)	65.50±14.70	

*t-test, **ANOVA test, ***Kruskal-Wallis test

Table 2: Pearson correlation between PTG and the perceived SS among the caregivers

	SS	Family	Friends	Others
PTG (total)	P<0.001	P<0.001	P<0.001	P<0.001
	r=0.595	r=0.59	r=0.42	r=0.44
New possibilities	P<0.001	P<0.001	P<0.001	P<0.001
	r=0.500	r=0.47	r=0.38	r=0.37
Relating to others	P<0.001	P<0.001	P<0.001	P<0.001
	r=0.653	r=0.57	r=0.54	r=0.49
Personal strength	P<0.001	P<0.001	P=0.02	P<0.001
	r=0.414	r=0.48	r=0.21	r=0.30
Appreciation of life	P<0.001	P<0.001	P=0.022	P=0.003
	r=0.38	r=0.44	r=0.21	r=0.28
Spiritual change	P<0.001	P<0.001	P=0.02	P=0.004
	r=0.35	r=0.39	r=0.21	r=0.27

PTG dimensions: *personal strength* (r=0.73), *appreciation of life* (r=0.65), and *relating to others* (r=0.64), whereas *spiritual change* (r=0.52) had the lowest correlation (Table 3).

The results of multiple regression analysis showed a significant relationship between PTG, perceived SS, and hope (P<0.001). Based on the results, if the hope was kept

constant, a 1-unit change in the perceived SS score affected the PTG score by 0.35. Also, when the perceived SS was kept constant, a 1-unit change in the hope score affected the PTG score by 0.42. It was observed that hope (β=0.62) had a higher effect on PTG compared to the perceived SS (β=0.27) (Table 4).

Table 3: Pearson correlation between PTG and hope among the caregivers

PTG	Correlation coefficient	P value
Total PTG	0.70	<0.001
New possibilities	0.62	<0.001
Relating to others	0.64	<0.001
Personal strength	0.73	<0.001
Appreciation of life	0.65	<0.001
Spiritual change	0.52	<0.001

Table 4: The correlation among PTG, hope, and the SS based on multiple regression analysis

Model	Coefficients				R square
	Unstandardized		Standardized		
	Beta	SD	Beta	P value	
Hope	0.42	0.04	0.62	P<0.001	0.64
Social support	0.35	0.08	0.27	P<0.001	

DISCUSSION

The results of this study showed a good level of PTG among the caregivers of cancer patients. This positive change was associated with the perceived SS and hope; however, hope had a higher effect on PTG compared to SS.

Cancer is a traumatic experience for both the patients and their family caregivers. Nonetheless, positive outcomes may emerge by channeling the pain from such traumatic experience into positive, productive, and meaningful growth through finding meaning in the experience, defining a new set of goals, and proactively trying to achieve them.³¹ The findings of the present study indicated a higher potential for PTG among Iranian cancer patients and family caregivers. Various degrees of PTG have been reported in studies among cancer patients^{14, 15} and the caregivers (parents) of children with different types of cancer.^{13, 22} In comparison, the mean score of the PTG dimensions in our participants was higher than the above-mentioned reports. In line with other studies,^{32, 33} we also believe that religion and spirituality play an important role in the ability of the Iranians to experience traumatic events in a positive way.

The results of the present study showed a significant relationship between PTG and sex as well as marital status. Among all demographic characteristics, the male and

married caregivers had the highest score. In contrast, a descriptive study reported no correlation between PTG and demographic characteristics.²² Moreover, another study showed that women experienced more PTG than men.¹⁹ Such contradictory findings could be due to different socio-cultural contexts and demographic characteristics.

Our results showed a high level of perceived SS among caregivers. However, an average level of perceived SS during the initial 3 months after the diagnosis of oral cancer was reported in Taiwan.³⁴ Again, the difference could be caused by the variation in socio-cultural environments and the duration of care by caregivers. The collectivist nature of Iranian society (close family ties and social relationships) could have played a positive role in coping with the disease and accepting the burden of care.³⁵ Our results further showed a positive correlation between the score of the perceived SS and PTG among the caregivers. Similar results were also reported in other studies, but among patients rather than caregivers.^{5, 24} It seemed that the perceived SS was a powerful notion in confrontation with challenges and stresses. When one is confident of the support of others in times of need, the feeling of hopelessness and weakness can be overcome. As a direct result, it would be possible to effectively deal with all sorts of problems in life. It is in this

context that new relationships are formed and interactions take place, leading to a higher level of satisfaction in life.³⁶ In a previous study, a positive correlation between the perceived SS and active coping strategies was reported. It seems that active coping strategies and perceived SS were the main factors of PTG. In other words, a more proactive rather than a passive approach would increase the chance of PTG when facing with stressful situations.²³

Perceived SS had the highest effect on PTG dimensions: *relating to others*, *new possibilities*, and *personal strength*, whereas *spiritual change* had the lowest correlation. Perceived SS refers to the ability and quality of interaction with others to develop ways to counter stressful conditions (e.g., cancer), and to gain benefit and meaning from the experience.³⁷ Therefore, it is logical to observe its correlation with the PTG dimensions *new possibilities* (allowing a better understanding of possibilities and consequences) and *relating to others*. On the other hand, PTG had the highest and the lowest correlation with *family* and *friends*, respectively (both dimensions of perceived SS). In line with our findings, the results of two other studies showed that the perceived SS from the family would contribute to coping with the disease and result in PTG.^{35, 38} Considering the importance of a close family bond and emphasis on family support and teamwork in Iran, we found a high level of perceived SS among our participants. The majority of our caregivers were either the spouse or children of the cancer patient, and in turn, they were supported by other family members. Based on these outcomes, we recommend the use of perceived SS in interventional programs to improve the psycho-spiritual and well-being of both the patients and their caregivers.³⁹

In the present study, the level of hope among the participants was high. Hope means being dominated by life, feeling of power and discretion, and sense of collective purpose and focus on higher goals.²¹ It improves the physical and physiological conditions, quality

of life, and is a crucial element to fight with stress.⁴⁰ The more realistic the hope is and the more one is aware of it, the more effective and efficient it is to resolve the problems.⁴¹ We found a significant positive relationship between the scores of hope and PTG. In line with our results, a higher mean score of hope among the caregivers was reported in another study.²² Our results showed a significant effect of hope on the PTG dimensions: *relating to others*, *new possibilities*, and *personal strength*, whereas it had the least effect on *spiritual change*. A study among the parents of children with cancer reported that hope was associated with higher scores in the PTG dimensions: *relating to others*, *new possibilities*, *personal strength*, and *appreciation of life*. People with a higher level of hope displayed more flexibility; they adjusted their goal according to the new situation, which in turn resulted in PTG in the dimension of *new possibilities*. Moreover, such individuals were part of a broad and active network of people, which enabled them to deal with stressful situations.

Based on our results, the *spiritual change* had the least correlation with hope and perceived SS. This could be due to the fact that *spiritual change* occurs over a longer period of time and is influenced by various factors. Saturation could also affect the results such that no further improvement in *spiritual change* would be observed if caregivers already had strong religious beliefs prior to the cancer diagnosis of their patients.²²

Compared to the perceived SS, hope had a higher effect on PTG, probably because of the fact that hope is an inner force⁴¹ and can exist even without perceiving SS since it is intrinsic to a person, whereas SS is rooted in the society. A caregiver without hope may experience a lower level of perceived SS despite a broad social network.

The findings of the present study would have certain clinical implications for healthcare providers and nurses in particular. These professionals should be aware of the fact that traumatic events may lead to growth

in the family caregivers of cancer patients. Considering the fact that family caregivers play an important role in providing care and continuity of treatment in cancer patients, health care service providers and nurses should pay more attention to their physical, psychological, social, and spiritual needs. Therefore, it is necessary to examine the extent of PTG in patients and their caregivers. In addition, certain measures should be taken to foster PTG in caregivers, particularly through strengthening hope and enhancing SS.

The main strengths of the present study were its multi-center design as well as validated and localized data collection instruments. The main limitation of the present study, beyond our control and due to the nature of the disease, was the effect of pressure on the caregivers and their mental status which could have adversely affected their response to the questionnaires.

CONCLUSION

Family caregivers of cancer patients are also exposed to a traumatic experience and its subsequent stress and challenges. However, similar to patients, they may also experience PTG. We observed a high level of PTG, hope, and perceived SS among the participants of the present study. A significant positive relationship was found between PTG and perceived SS as well as hope. In order to foster PTG in family caregivers, the findings of the present study could help health care providers and especially nurses to implement a scheme with the aim of strengthening both hope and the perceived SS. This scheme should include periodic counseling, encouragement of patients and caregivers to participate in communities, the provision of facilities for religious practices, facilitation of spiritual care to enhance spiritual growth, and the provision of peer support groups.

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