



# Posttraumatic growth in bereaved family members of patients with cancer: a qualitative analysis

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## Abstract

**Background** The death of a loved one has great impact on family members even when the death was expected. While negative changes are reported, some individuals also report personal growth, known as posttraumatic growth (PTG). Many studies on PTG have been performed using quantitative methods and suggest that PTG may differ according to the traumatic event and cultural background.

**Purpose** This study aimed to explore how Japanese bereaved family members of patients with cancer express their experience of PTG after the patient's death by analyzing open-ended answers provided in a cross-sectional survey.

**Methods** Qualitative data were collected through a survey, and thematic analysis was used to analyze the data. The present study was part of a larger cross-sectional survey of bereaved families of patients with cancer. Data analyzed in the current study were obtained from 162 bereaved family members of patients with cancer.

**Results** We identified 18 sub-themes within five predefined major domains of PTG. Moreover, we also identified two additional themes: *changed view of life and death*, and *awareness of health management*.

**Conclusions** The experience of PTG of bereaved family members varied considerably. Future research on PTG experiences among groups from diverse cultural backgrounds would be beneficial for understanding the concept and its clinical implications.

**Keywords** Bereaved family · Cancer · End-of-life care · Home palliative care · Posttraumatic growth · Qualitative analysis

## Introduction

The death of a loved one may greatly impact family members even when the death was expected. Previous studies indicated that bereaved family members experience negative changes such as depression, despair, anger, and lowered self-esteem [1–3]. Furthermore, 7–20% of bereaved family members experience complicated grief [4–6]. However, while grieving,

some individuals also report positive changes. Gilmer et al. [7] indicated that bereaved family members reported positive changes such as shifting perspectives, reconsidering priorities, increasing spiritual beliefs, and building stronger relationships with family and friends.

Due to the psychological struggle during a highly stressful life event, such as losing a family member, some individuals might experience psychological growth, known as posttraumatic growth (PTG) [8], defined as positive psychological changes as a result of the struggles in highly challenging life circumstances [9]. Tedeschi and Calhoun developed the PTG Inventory (PTGI) [8] to measure PTG quantitatively. It comprises five domains: *relating to others*, *new possibilities*, *personal strength*, *spiritual change*, and *appreciation of life*. However, only two items on the PTGI assess *spiritual change*. Recently, its expanded version was developed [10], which has a five-factor structure: *relating to others*, *new possibilities*, *personal strength*, *spiritual and existential change*, and *appreciation of life*, and four newly developed items of *spiritual and existential change* were added. PTG is relatively common following the death of a loved one; most bereaved family members report some degree of PTG [11, 12].

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A theoretical model describing the process leading to PTG presents several psychosocial factors (e.g., the type of trauma, individual characteristics pre-trauma, rumination, and socio-cultural influences) [9, 13]. Many studies on PTG have used quantitative methods, and it was found that Japanese individuals, for example, tend to report a lower level of PTG than do their American counterparts [14, 15]. Research has shown that PTG is affected by not only cultural background but also the type of traumatic event (e.g., death of loved one).

Many patients with cancer in Japan prefer staying at home at the end of their life [16]. Family members of patients with cancer who die at home are generally more satisfied than those whose family member dies in hospital [17, 18]. Patients with cancer might feel more secure and at peace, and be able to reflect on their memories when staying at home [19, 20]. It has been reported that the quality of patient's death (e.g., place of death) is positively associated with PTG of bereaved family members [21]; therefore, patients staying at home at the end of life may influence bereaved family members' PTG.

Exploring the nature of PTG among Japanese bereaved family members using a qualitative approach may help to understand how they express and experience PTG. The findings of this study may be informative when providing appropriate support to bereaved family members. This study aimed to explore how Japanese bereaved family members of patients with cancer express PTG resulting from the patient's death, by analyzing open-ended descriptions provided in a cross-sectional survey.

## Methods

### Data collection

The present study was part of a larger cross-sectional survey of bereaved families of patients with cancer. Convenience sampling was used. A researcher (KH) approached three home care agencies registered with the Japan Home Hospice Association. In the anonymous questionnaire survey, open-ended responses to the prompt, "Please describe anything you have noticed or thought about as a result of losing your family member because of cancer" were collected.

### Demographic data of patients and participants

Demographic data of the patients (age, gender, primary cancer site) and their family members (age, gender, relationship with the deceased, religious status) were collected and analyzed. The item religious status was open-ended, and responses were coded as Buddhism, Christianity, and Others.

## Participants

Inclusion criteria of respondents were as follows: (a) bereaved family members of an adult patient with cancer who died after receiving palliative care at home, (b) aged  $\geq 20$  years, and (c) capable of completing a self-report questionnaire. Exclusion criteria included the following: (a) inability to complete a self-administered questionnaire (e.g., dementia, cognitive incapability, psychiatric illness, language difficulty, visual loss, or own decision), and (b) family member unavailable.

Bereaved family members ( $n = 1861$ ) who had experienced the death of a relative with cancer at home between January 2008 and December 2012 were eligible to participate in the study. Participating agencies sent the anonymous questionnaires to the family members in November 2013. Many previous PTG studies, including the original study developing the PTGI [8], used a 5-year interval from the traumatic event. Therefore, we used the same period for this study. This study was approved by the Tokyo Medical and Dental University Review Board (Number 1504).

## Data analysis

A qualitative study analysis was performed for this study. Prior to the analysis, responses were rated as follows: "overall positive," "overall negative," "both positive and negative," and "other" by three independent researchers (KH, SI, and HF). We defined "positive" as expressing or implying affirmation, agreement, or permission, showing progress or improvement, and "negative" was defined as expressing or implying denial, disagreement, or refusal [22]. Responses rated either "overall positive" or "both positive and negative" were then analyzed using thematic analysis [23, 24]. Thematic analysis involves identifying, analyzing, and reporting the patterns (themes) in the data [24]. The strengths of this approach are that it can summarize the key features of a large body of data and highlight the similarities and differences across the dataset [24]. There are three methods of developing the thematic codes: (1) theory-driven (i.e., a PTG model), (2) prior data or prior research-driven, and (3) inductive or data-driven. These approaches can be considered to form a continuum from theory-driven to data-driven approaches [24]. We adopted both theory- and data-driven methods for this study.

First, three researchers (KH, SI, and HF) independently read the responses line by line, and two of them (KH and SI) identified preliminary codes and potential themes following the five major PTGI domains [10, 25]. Second, any transcript data that could not be classified with the initial coding/domain were given a new code. The codes' sub-themes and themes were compared and discussed through the process. Subsequently, two different researchers (TK and AO) checked the validity of themes and descriptions, and themes were revised accordingly.

All researchers checked and confirmed the results. In this study, a theme refers to a pattern observed in the information that at the minimum describes and organizes the possible observations or at the maximum interprets the aspects of the phenomenon [23]. Sub-themes can be useful for giving a structure to a particularly large and complex theme, and also for demonstrating the hierarchy of the meaning within the data [24]. When we refer to the five areas of the PTGI, we use the word “domain,” and when we describe the results of the current study, we use the word “theme.” We followed the consolidated criteria for reporting qualitative research (COREQ) [26].

## Results

Of the 1861 questionnaires sent, 955 were completed; 128 questionnaires did not reach the families because of incorrect/unknown address. In total, 391 participants (21.0%) provided open-ended responses. Of these, 174 (45.9%) participants’ responses were rated as “overall positive,” 110 (28.1%) as “overall negative,” and 71 (18.2%) as “both positive and negative.” Three participants (0.8%) responded “Nothing” and 33 (8.4%) provided general comments such as “Maybe because I’m getting older, I do not really think about anything,” which were thus coded as “other.”

Of the 245 participants whose responses were rated as either “overall positive” or “both positive and negative,” 83 provided positive descriptions related to a good death, such as observing a peaceful death (e.g., “I am glad that she/he passed away without suffering”), expression of gratitude by the deceased (e.g., “It was comforting during the time that she said how thankful she was to our children and myself while taking care of her”), and appreciating the support of medical staff (e.g., “Thanks to doctors and nurses, I was able to take care of her/him until the end”). Because PTG is conceptualized as personal growth that occurs as a result of a psychological struggle, rather than the event itself, we eliminated these participants’ descriptions and analyzed the remaining 162 (41.4%) participants’ responses. Table 1 shows participants’ demographic characteristics and information on the deceased patients.

Data were classified into 23 sub-themes, of which 18 were identified under the five PTG domains in the Expanded PTGI (six under *relating to others*, four under *new possibilities*, two under *personal strength*, three under *spiritual and existential change*, and three under *appreciation for life*). Two additional themes were identified to cover the remaining five sub-themes: *changed view of life and death*, and *awareness of health management* (Table 2). PTG descriptions classified into each domain are described below.

**Table 1** Demographic/medical characteristics of participating family members ( $n = 162$ ) and deceased patients

		<i>n</i>	%
		Mean (SD)	
<b>Patients</b>			
Age (years)		72.5 (12.2)	
Gender	Male	105	64.8
	Female	55	34.0
	Missing	2	1.2
Primary cancer site	Lung	41	25.3
	Stomach	26	16.0
	Colon	15	9.3
	Liver	15	9.3
	Pancreas	13	8.0
	Other	51	29.6
	Missing	1	0.6
	<b>Bereaved family members</b>		
Age (years)		61.4 (13.5)	
Time since death (years)		2.7 (1.3)	
Gender	Male	25	15.4
	Female	133	82.1
	Missing	4	2.5
Relationship with the patient	Spouse	83	51.2
	Child	60	37.0
	Other	14	8.7
	Missing	5	3.1
Religious belief	None	72	44.4
	Yes	85	52.5
	Missing	5	3.1
Type of religion	Buddhism	62	38.3
	Christianity	15	9.3
	Missing	85	52.5

## Changed view of death and life

After the death of the patient with cancer, some family members became aware of their own death and dying and showed signs of thinking about the afterlife.

### Being aware of my own death

Some participants became aware of their own death through the death of their relatives with cancer.

“My husband certainly does not exist anymore, but I feel like I always stay with him in our house together. I often think how I am going to die, because I will be next.”

**Table 2** Posttraumatic growth reported by bereaved family members

Themes	Sub-themes
Changed view of life and death	Being aware of my own death
	Preparing for my own death
	Better understanding of death
	Having interest in the afterlife
Awareness of health management	Being aware of health management
	Relating to others
Relating to others	Recognizing the value of the family
	Strengthening family bonds
	Support from others
	Accepting the need for support from others
	Having compassion for others
	Finding comfort by interacting with others in a similar situation
	New possibilities
Developing new interests	Developing new interests
	Trying new challenges
	Establishing new pathways
	Having a purpose in life
Personal strength	Becoming mentally stronger
	Recognizing that I can handle difficulties
Spiritual and existential change	Feeling the deceased always close to me
	Talking to the deceased
	Protected by the deceased
Appreciation for life	Appreciating the value of my life
	Appreciating each day
	Having a pleasant life

### Preparing for my own death

Bereaved family members described having ideas about their own death and preparing for it.

“My husband could not take anticancer drugs, and I was bewildered by the speed of his body becoming weaker. From this experience, I have decided to testify to my family while my consciousness is clear. I will prepare for the end of my life.”

### Better understanding of death

Some participants noticed changes in their understanding of the universality of death and described less fear of death.

“I felt less afraid of death. It seems very natural for everyone to experience ‘death.’”

### Having interest in the afterlife

Family members reported changes in their interest in and better understanding of afterlife.

“Although I don’t want to die, I’m ok if I die of a disease, because I believe I can see my wife in the afterlife (This feeling may not sound normal, but it is how I honestly feel now).”

### Awareness of health management

Two participants described their awareness of the importance of health management.

“I started taking better care of my health. I go to see a doctor for early detection and treatment.”

### Relating to others

Some participants described changes in their relationships with others, including other family members and friends, through caring for a patient with cancer at home.

### Recognizing the value of the family

Some of family members became aware of the value of the family.

“After the death, I lived alone for a while. I realized that my family is the most precious and greatest thing to me.”

### Strengthening family bonds

Participants reported strengthening family bonds through caring for a patient with cancer at home with other family members.

“My mother died at home. Because she lived on her own, I would not have been able to take care of her while staying at her house without the understanding of my family. Because of that, I felt that the bond with my family became stronger after my mother’s death.”

### Support from others

Bereaved family members reported receiving support from others.

“When my mother died, I could not find any meaning in my life. But as time went by, I found happiness and reason to live. I was really glad because I got support from others. It was precious to me. I became more optimistic after the one-year anniversary of her death.”

### Accepting the need for support from others

Some family members described the importance of accepting support from others.

“After the death of my wife, I realized how lonely and hard it was to live alone, especially after we got older. Luckily, I was invited to a bereavement program held in the home palliative care, then I finally found the way to live the rest of my life through listening to other participants’ experiences or taking advice. I really feel the importance of psychological support from others.”

### Having compassion for others

Some participants described having empathy for others.

“After caregiving and experiencing the death of my father, I feel sorry for the death of other people I know much deeper than before.”

### Finding comfort by interacting with others in a similar situation

Some family members described feeling consolation when they met or talked with others who were in a similar situation.

“My children do not understand the loneliness of an old-aged woman living alone. Luckily, because most women in their eighties also lost their husbands, I feel relieved when I meet with same-age widows.”

### New possibilities

Family members found new interests or pathways, and described trying new challenges.

### Developing new interests

Some participants described having expanded their interests.

“Because of the support from my family and friends, I was able to overcome the death. So, I think it’s my turn to do something for other people.”

### Trying new challenges

Family members attempted to do new things.

“I realized that death is inevitable for everyone. So, I began to think seriously how I am going to die. Also, I realized that living means enjoying something with a purpose and, so I am trying to challenge something as much as possible.”

### Establishing new pathways

Participants developed new pathways.

“I decided to be a care worker after I took care of my mother when she died at home. Now, four years have passed since I became a care worker, and I wish I could have done more like this to my mother. I regret it sometimes. But I think that my mother guided me to the current job and I am trying to convince myself by taking care of other people who are the same age as my mother.”

### Having purpose in life

Some participants described how they want to live their life.

“I thought deeply about my mother’s death, and I thought over my life and also realized the meaning and preciousness of life. I am trying to make use of my mother’s death for raising my children to continue our lives, and I believe that it will be for my mother’s soul.”

### Personal strength

Bereaved family members reported feeling a stronger bond with the deceased.

### Becoming stronger

Participants reported that the deceased made them stronger because they gave their power to bereaved family members.

“I think my husband is living in my mind. I felt that I became stronger than before because my husband is giving me his power.”

### Recognizing I can handle difficulties

Some bereaved family members noted that they could handle difficulties.

“I feel very sad because I cannot see him anymore, but death is not a bad thing and it will come to me some day, too. I would like to live by cherishing each moment and I felt I was able to accept everything at the same time.”

### Spiritual and existential change

Participants reported continuing the connection and bond with the deceased and becoming aware of the meaning of life.

### Feeling the deceased always close to me

Participants felt the deceased was always close to them and/or lived in their mind.

“Although my father pulled off his body (at his death), he was relieved from pain. His soul is immortality and I feel that he is always with me. In my mind, my father is happier now than before.”

### Talking to the deceased

Some participants described talking to the deceased in their mind or in front of an altar.

“I talk with her (mother-in-law) every morning and evening in front of the Buddhist altar.”

### Protected by the deceased

Family members described the feeling of being guarded by the deceased.

“I feel that my parents are my guardian spirits and I come to appreciate everyday things. Since I cannot know when I will die, I appreciate each day. Even when the day comes to me, I will not have any regrets.”

### Appreciation for life

Participants reported appreciating each day of their lives.

### Appreciating the value of my own life

Some participants described appreciating the worth of their life.

“It is sad to be unable to meet with the deceased, but I think that death is not a bad thing, and I will die someday, too. So, I appreciate the day, at the same time I thought I can accept everything.”

### Appreciating each day

Some bereaved family members experienced gratefulness for each day.

“It is important to live day by day as much as I can.”

### Having a pleasant life

Family members reported enjoying their life or living happily each day.

“After the death of my husband, I thought of various things that had happened in our house for 2 months, but now I wish to enjoy my life, and I am going out with my friends 4 days a week. I feel bad for my husband, but I spend every day happily and do well. I visit my husband’s grave on the monthly anniversary of his death.”

## Discussion

This study is the first to describe PTG among Japanese bereaved family members of patients with cancer. The qualitative data revealed detailed sub-themes in five broad PTG domains and identified two additional themes: *changed view of life and death*, and *awareness of health management*. Our results may facilitate understanding PTG among those with this specific cultural background.

Two new themes, *changed view of life and death*, and *awareness of health management*, were identified in the current study. Although the *changed view of life and death* theme may overlap with one of the five PTG broad domains, *spiritual and existential change*, we interpreted it as a distinctive aspect of PTG in bereaved individuals. Previous studies found an increased acceptance of mortality [27] and belief in afterlife

[28] as examples of growth experiences among bereaved persons, and these findings are consistent with our results. Because patients received palliative care at home, bereaved family members may become aware of the reality and universality of death, and consider preparing for their own death. Previous studies have also reported awareness of health management among family members of patients with cancer [29, 30]. Bereaved family members realized the importance of health management through witnessing cancer detection and prognosis. This theme may overlap with one of the five domains of PTG, *new possibilities*. However, we distinguished this theme because it was also a characteristic of family members of patients with cancer (e.g., cancer risk).

In the theme *spiritual and existential change*, the sub-themes *feeling the deceased always being close to me*, *talking to the deceased*, and *protected by the deceased* were identified. These sub-themes are linked to maintaining the connection with the deceased. A recent quantitative study found that an internalized continuing bond with the deceased was associated with a higher PTG [31]. Furthermore, bereaved family members benefited from continuing to feel the presence of the deceased [32]. Maintaining a bond with the deceased may provide security and certainty for the bereaved, and these feelings may foster PTG.

As shown in the sub-theme of *talking to the deceased*, some participants talked to the deceased in their mind or in front of an altar. Many people in Japan prepare a place for an altar or a photo of the deceased in their house, which may provide family members a chance to talk to the deceased in their daily living. A recent study reported that PTG was positively associated with the act of “putting palms together in front of deceased’s photo/altar” [33]. In the current study, bereaved family members took care of patients at home. Home is associated with the expression of social and cultural identity, including symbolic and affective connections [34]. Through caring for the patient with cancer at home, bereaved family members might feel a connection with the patient even after the death.

Some family members reported becoming stronger because the deceased was living in their mind or giving them energy. Similar changes were reported in a previous study [35], suggesting that this type of PTG might be unique to bereaved individuals. Because bereaved family members often perceive benefit in continuing to feel the presence of the deceased [26], they might feel stronger. These changes may be associated with spiritual and existential changes.

Although 52.5% of our participants reported having a certain religious affiliation, descriptions specific to religion were not found in the current study. This is in contrast with previous studies that identified PTG as an increased belief in religions or God [27, 30] or changes in life priorities [29, 30]. Religious belief was found to be associated with PTG [36, 37] both in Western countries and Japan. However, religious rituals are

customary in Japanese people’s daily lives; therefore, bereaved individuals may not experience religious changes. This may explain the lower levels in the *spiritual and existential change* domain reported by the Japanese participants; however, additional research will be required.

In this study, we identified 23 sub-themes, such as “feeling the deceased always being close to me,” “talking to the deceased,” and “protected by the deceased” (in the theme spiritual and existential change). These detailed descriptions could be useful for clinicians to understand the unique feature of the PTG experienced by bereaved family members. In addition, the findings of this study might inform clinicians that cultural influences on PTG might be also useful for fostering the personal growth of the bereaved family members.

### Strength and limitations

This study has several limitations. First, because of the retrospective nature of cross-sectional questions, the descriptions of participants might have been limited. Second, as we adopted convenience sampling through specialized home palliative care agencies, selection bias might exist. Third, because 1 to 5 years had elapsed since the patients’ death, there might be recall bias. The study participants were limited to family members of patients with cancer who received palliative care at home; therefore, caution should be exercised when generalizing the findings to other groups and contexts. Despite these limitations, this study describes the PTG of Japanese bereaved family members and it is important that clinicians understand these unique experiences. Future research should investigate the PTG experience through in-depth interviews.

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### Compliance with ethical standards

Primary data for this study is held with authors named on the Tokyo Medical and Dental University Review Board Ethics Approval. Data cannot be reviewed externally for ethical reasons.

**Conflict of interest** The authors declare that they have no conflict of interest.

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