

## Original Manuscript

Growth Experience
Bereaved of a Spouse by
Cancer: Relying on
Merleau-Ponty's
Reorganization of the Body
Schemes

OMEGA - Journal of Death and Dying 2023, Vol. 0(0) 1–22 © The Author(s) 2023 Article reuse guidelines: sagepub.com/journals-permissions DOI: 10.1177/00302228231164859 journals.sagepub.com/home/ome

**\$**SAGE

Megumi Kondo<sup>1</sup>, Tomoki Kihira<sup>2</sup>, Yukihiro Sakaguchi<sup>3</sup>, Kazuki Shimada<sup>4</sup>, Yuki Shirai<sup>1</sup>, and Keiko Tamura<sup>1</sup>

#### **Abstract**

The grief experienced by bereaved families can lead to positive changes, and its relevance to the emerging concept of posttraumatic growth has been explored. However, studies on survivors bereaved of a spouse by cancer are scarce; consequently, the nature of growth remains poorly understood. This study aimed to explore the growth experiences of survivors bereaved of a spouse by cancer. Based on Merleau-Ponty's theory of the body, we phenomenologically analyzed narratives/qualitative data collected through interviews of 21 survivors bereaved of a spouse by cancer. The assessment of the growth of survivors bereaved of a spouse by cancer began before the bereavement, with the questioning of habits with the living spouse because of illness and prognosis announcement and/or bereavement, reaffirming the connection with the spouse, realizing that it provides emotional support, and becoming accustomed to who they are now in the new environment.

#### Corresponding Author:

Megumi Kondo, Department of Palliative Nursing, Graduate School of Medicine, Kyoto University, 53 Shogoin Kawahara-Cho, Sakyo-Ku, Kyoto 606-8507, Japan.

Email: kondo.megumi.7x@kyoto-u.ac.jp

<sup>&</sup>lt;sup>1</sup>Department of Palliative Nursing, Graduate School of Medicine, Kyoto University, Japan

<sup>&</sup>lt;sup>2</sup>College of Nursing Art and Science, University of Hyogo, Japan

<sup>&</sup>lt;sup>3</sup>School of Human Welfare Studies, Kwansei Gakuin University, Japan

<sup>&</sup>lt;sup>4</sup>Department of Palliative Medicine, Kyoto University Hospital

## **Keywords**

grief, bereavement, spouses, Merleau-Ponty's theory of the body, qualitative study

## Introduction

Approximately 10–25% of bereaved families who have lost a loved one suffer from complicated grief (Aoyama et al., 2018; Lobb et al., 2010; Miyajima et al., 2014), and in particular, approximately half of bereaved families who have lost a spouse show high depressive symptoms even two years after the loss (Yopp et al., 2019). Therefore, grief is considered a stressful experience for bereaved families, and researchers have been studying their recovery (Neimeyer, 2001; Stroebe et al., 2001). However, since the 1990s, the research focus has shifted to positive aspects of stress (Schaefer & Moos, 1992). Along these lines, Tedeschi & Calhoun (1995) assumed that stress could trigger growth, and developed empirical tests of the new concept of posttraumatic growth (PTG). Subsequently, they based their theory of the PTG model on these empirical tests (Tedeschi et al., 1998).

Given the positive aspects discussed in the field of stress research, it has been suggested that grief can also be a positive, transformative experience for grieving families (Gilmer et al., 2012). The development of the Posttraumatic Growth Inventory (PTGI), a scale measuring PTG, by Tedeschi et al. (Tedeschi & Calhoun, 1996), expanded the scope of PTG research (Helgeson et al., 2006). Additionally, studies on families and survivors of cancer patients in the pediatric setting (Arslan et al., 2020; Irie et al., 2021; López et al., 2019; Slaughter et al., 2020) have been increasing. Studies of adult family members are limited to a literature review (Lee & Lee, 2020) of families of cancer patients in Korea, a conceptual analysis of PTG in families of cancer patients (Kim & Shin, 2019), and a study of the families of gastrointestinal cancer patients in Iran (Nouzari et al., 2019). In Japan, the development of the Japanese version of the PTGI based on Tedeschi et al.'s PTGI (Taku et al., 2007) led to a number of quantitative studies on factors related to PTG in bereaved families who had lost a family member to cancer. As a result, the following factors have been found to be associated with PTG: the patient's quality of death (Hirooka et al., 2017), and bereaved family members' religious beliefs, age, and length of time since bereavement (Hirooka et al., 2018). On the other hand, qualitative studies of bereaved families of cancer patients have found considerable variation in the PTG experiences of bereaved families, suggesting that research on the PTG experiences of individuals from diverse cultural backgrounds is needed (Hirooka et al., 2019). Owing to the lack of relevant research, the nature of PTG among survivors bereaved of a spouse by cancer lack clarity. Calhoun and Tedeschi (2010) presented a growth model that builds on their previously proposed growth model (Tedeschi & Calhoun, 2004). In the new model, growth requires significant challenging of assumed beliefs, cognitive and emotional effort, and a narrative component. However, this model focuses on changes in the role of cognitive processing, or ruminating, and does not adequately show clear changes in the life narrative.

To better understand bereaved families' growth, it is necessary to clarify the changes in the life narrative of the bereaved, that is, the nature of growth for the bereaved. Thus, we explore survivors' growth after the bereavement of a spouse by cancer.

## **Methods**

## Design

Phenomenology is a methodology for gaining new insights and a more comprehensive understanding by returning to the events of the experience itself (Toombs, 2001). PTG is a concept that includes not only the outcome but also the process beginning immediately after the trauma (Tedeschi et al., 1998). As it is a complex phenomenon (Tedeschi & Calhoun, 2008), a comprehensive understanding of PTG is necessary. Hence, a phenomenological approach was chosen for this study. Methods and results are described by the Standards for Reporting Qualitative Research (SRQR) checklist (O'Brien et al., 2014).

## **Participants**

Purposive sampling was used to recruit bereaved spouses aged 40 years or older. We considered it important to capture the trajectory of survivors bereaved of a spouse with reference to previous studies (Maciejewski et al., 2007). Therefore, the inclusion criteria were struggling for at least six months through the patient's illness and surviving for more than six months and less than 10 years.

#### Recruitment

Participants were recruited by a clinical psychologist specializing in grief and bereavement care after death (Y.S.), a palliative care physician (K.S.), a physician
working in a palliative care unit, a physician involved in bereavement associations, and
a member representing a bereavement association. Recruiters selected individuals who
met the selection criteria based on bereaved families' testimony. Additionally, the
recruiters asked bereaved family members, either in person or over the phone, "I know
that losing a loved one is a very painful experience, but is there anything that you think
has changed or is different about you after going through such a painful experience?" to
see if the bereaved family members were aware that they had changed. To the
21 survivors (eight men and 13 women) who were aware that they had changed, the
recruiters sent a description of the research, asked the survivors if they were willing to
participate, and obtained their consent to participate over the phone. Additionally, one
researcher (M.K.) apprised the bereaved families of the study verbally and in writing.
No one refused to participate at this time, and written consent was obtained from
21 bereaved families. It was decided that no new results could be obtained by further

increasing the number of participants, and referring to previous studies (Silva et al., 2018; Tang & Lee, 2017), recruitment was stopped at 21 participants.

#### Data Collection

Forty-one semi-structured interviews were conducted between July 2019 and March 2021. Although developed based on the PTG conceptual framework, the interview guide was adapted as M.K. conducted pilot interviews with representative members of the bereaved association (Table 1). Two rounds of semi-structured interviews were conducted on Zoom and by telephone by M.K. in April 2020 (only one participant was absent for the second interview). The second interview was conducted to verify whether the content regarding the meaning of growth revealed by the analysis of the results of the first interview was consistent with the participants' thoughts. The period between the first and second interviews averaged 8.8 months (4-12 months). The first and second interviews lasted an average of 69 and 26 minutes, respectively. Participants' ages ranged from 57 to 90 years, 58 to 90 years (mean 74.5) for men, and 57–81 years (mean 68.0) for women. Participants had been bereaved for 11 months to eight years, and 16 were religious (13 Buddhist, one Christian, and two other/unknown). Spouses who died of cancer had an age range of 52–84 years, 52–82 years (mean 67.1 ayears) for men, and 58-84 years (mean 68.4 years) for women. Spouses who died of cancer were in treatment from six months to 20 years, and died in a Palliative Care Unit (PCU), general ward, or at home (Table 2).

## Data Analysis

The interviews were recorded and transcripts were prepared by an outside contractor, which was subsequently reviewed by M.K. The analysis started immediately after the

Table I. Interview Guide.

Step	Contents
Introduction	I Would like to ask you about your experience from the time your husband/wife was diagnosed with cancer until now.
	I Know that losing a loved one is a very painful experience, but what do you think has changed since you had such a painful experience?
Development	Do you feel that you have changed in your relationships with others?
-	Have you gained new interests or been inspired to take on new challenges?
	Do you feel that you have become stronger as a person?
	Have you ever felt a change in the meaning or mystery of life?
	Have you ever felt a sense of appreciation for life?
In the end	Are there any other memorable events that made you who you are today If so, how did that event change you?

Table 2. Demographic Data of Participants.

Paı	Participant Information	nform	nation						Spouse Information	nation	
	Gender	Age	Period Since Bereavement	Family Composition	Relig	Religious Beliefs	Gender Age	Age	Cancer Type	Period of Treatment	Location of Death
∢	A Female	99	5 years	Live with children	Yes	Other	Male	09	Cancer	Less than I vear	General
Ф	Male	63	Less than 3 years	Couple only	Yes	Buddhism	Female	29	Gastric cancer	Less than 2 years	PCU
O	Female	<del>∞</del>	Over 4 years	Live with children	ž		Male	82	Liver cancer	Less than 3 years	PCU
Ω	Female	7	Over 4 years	Couple only	Yes	Buddhism	Male	73	Prostate cancer	Less than 2 years	PCU
ш	Female	74	Over 4 years	Couple only	Yes	Buddhism	Male	69	Esophageal cancer	Less than 3 years	PCU
ட	Male	<del>∞</del>	8 years	Couple only	Yes	Yes Buddhism	Female	<i>2</i> 9	Cholangiocarcinoma	Less than 3 years	PCU
U	Male	83	Less than 2 years	Couple only	Yes	Buddhism	Female	9/	Breast cancer	20 years	PCU
I	Male	65	4 years	Couple only	°Z		Female	28	Breast cancer	Less than 2 years	PCU
-	Male	28	2 years 3 months	Live with children	Yes	Christianity	Female	28	Colorectal cancer	Less than 2 years	PCU
_	Female	7	11 months	Live with children	Yes	Buddhism	Male	20	Malignant lymphoma	Less than I year	Home
$\checkmark$	Female	65	65 4 years	Couple only	Yes	Other	Male	99	Lung cancer	Less than 3 years	General ward
_	Female	09	Less than 2 years	Live with children	Š		Male	62	Rare cancer	Less than 2 years	Home

(continued)

Table 2. (continued)

Par	Participant Information	nforn	nation					Spouse Information	mation	
	Gender Age	Age	Period Since Bereavement	Family Composition	Religious Beliefs Gender Age	s Gender	Age	Cancer Type	Period of Treatment	Location of Death
ΣΖ	M Male 73 N Female 65	73	Less than 3 years Less than 3 years	Couple only Couple only	No Yes Buddhism	Female Male	69 69	Breast cancer Gastric cancer	Over 5 years Less than	Home General
0	O Female	62	Less than 2 years	Live with children	°Z	Male	62	Esophageal cancer	Less than	Home
<b>△</b>	Male	83	2 years	Couple only	Yes Buddhism	Female	78	78 Lung cancer	Less than	PCU
0	Q Female	76	Over 4 years	Live with children	Yes Buddhism	Male	72	72 Gastric cancer	Less than 5 years	PCU
~	R Female	28	Less than 2 years	Couple only	Yes Buddhism	Male	63	Lung cancer	Less than I year	General
S	Female	72	Less than 4 years	Couple only	Yes Buddhism	Male	72	Pancreatic cancer	Less than I year	PCU
<b>-</b>	T Female	57	Over 4 years	Live with children	Yes Buddhism	Male	52	Lung cancer	Less than I year	PcU
$\supset$	Male	96	4.5 years	Couple only	Yes Buddhism	Female	84	84 Anal canal carcinoma Less than 3 years	Less than 3 years	PCU

Note. PCU = Palliative Care Unit.

interviews and was conducted per Giorgi's method (Giorgi, 2009). The specific analysis method is detailed below.

Analysis Method. Step 1. Read for a Sense of the Whole.

- 1. To understand the interview as a whole, the three researchers (MK, TK, KT) separately and carefully read the entire transcript verbatim to get an overview of the participant's overall narrative.
- 2. In repeated readings of the transcripts, the researchers highlighted the parts of the transcript that felt interesting and/or strange. By paying attention to the words and phrases used by participants and shifting perspective from the highlighted text of the narrative to the narrative as a whole, the researchers deduced the meaning of growth for the participants. These meanings were recorded in writing and used as a unit of meaning.

## Step 2. Determination of Meaning Units.

- 1. The three researchers examined the units of meaning they deduced and determined common units of meaning.
- For each unit of meaning identified, the recorded in writing as a unit of meaning was rewritten to go back to the participant's narrative to explore the connections that link the meaning units and to clarify the semantic content of the participants' growth.
- 3. Participants were interviewed again to verify that the content of the revealed meaning of growth is consistent with their thoughts.
- Step 3. Transformation of Participants' Natural Attitude Expressions into Phenomenologically and Psychologically Sensitive Expressions.
- 1. The meaning units established by the three researchers and the results of the re-interview were examined to identify the semantic content regarding participants' growth.
- 2. To generalize the semantic content of the growth of 21 survivors bereaved of a spouse by cancer, the semantic content was transformed into integrable expressions. The transformed expressions are checked by reference to the participants' narratives to determine whether they contain important meanings. This process is repeated until all meaning units have been converted.
- Based on the semantic content converted into integrative representations, the structure of growth for bereaved families, i.e., what the experience of growth looks like for them, is clarified.

*Philosophical Framework.* The theoretical framework of this study is based on the philosophical perspective of Merleau-Ponty's theory of the body (Merleau-Ponty, 2012). Merleau-Ponty opposes both scientific objectivism and idealistic subjectivism, which

presupposes a pure consciousness, and develops his theory of the body as an analysis of the ambivalent nature of existence, which is neither counter-self nor immediate self. Merleau-Ponty says: "my own body is the primordial habit, the one that conditions all others and by which they can be understood" (Merleau-Ponty, 2012, p. 93). Regarding the appropriation of the body as a habit, Merleau-Ponty says: "The body, then, has understood and the habit has been acquired when the body allows itself to be penetrated by a new signification, when it has assimilated a new meaningful core" (Merleau-Ponty, 2012, p. 148). In other words, the acquisition of a new habit can be understood as a "reorganization" and "renewal" of the body as a figure. The growth experienced by bereaved families who have lost a loved one occurs "when the death of someone close to them causes previously held beliefs to be challenged and emotional distress is caused by fluctuating beliefs, but through changes in cognitive processing, such as rumination, they recognize positive psychological changes by accepting the changed world" (Calhoun et al., 2010). Merleau-Ponty's theory of the body, the idea that habits are renewed and new habits are acquired through the reorganization of the body schemas that underlie experiences and actions, can be seen as analogous to "the growth of a bereaved family member who has lost a loved one." Therefore, the experience of a bereaved family member who has lost a loved one can be explained by Merleau-Ponty's theory of the body, in which the reorganization of habits leads to the acquisition of new habits, even though the experience is a matter of feelings such as grief and not strictly of the body. Given this, we thought it appropriate to use Merleau-Ponty's idea of the reorganization of habits based on his body theory as a philosophical basis for understanding what the nature of experience looks like for survivors who have lost a spouse to cancer.

#### Results

The analysis shows that for bereaved families, growth begins by questioning one's habits with the living spouse because of illness and prognosis announcement and/or bereavement, reaffirming the connection with the spouse, realizing that it provides emotional support, and becoming accustomed to who they are now in the new environment. Depending on the timing of the abovementioned triggers, the growth trajectories of the bereaved families were divided into three categories (Figure 1 and Table 3).

# Category I

Mrs. O and Mr. B describe their growth experiences as follows. The results show that the semantic unit for growth is the awareness/perception/behavior that the participant has experienced in their life; the period from cancer diagnosis to the present is denoted by  $[\ ]$ , the situation that causes the awareness/perception/behavior by  $\ll \gg$ , and the trigger that changes the situation by < >.

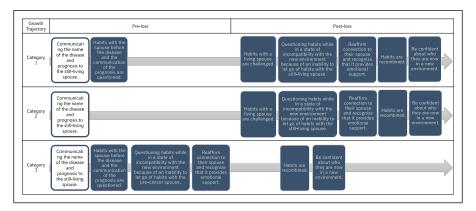


Figure 1. Category of growth trajectory for survivors bereaved of a spouse by cancer.

Actively Living Her Own Story After Losing Her Husband, Despite Wavering Emotions. When Mrs. O. learned that her husband had cancer, she lost the certainty that he would always be by her side and «did not know what to do anymore and was devastated».

When I was told he only had a year to live, I felt like I was lying on the ground... Like I was melting and falling into the mud. I thought, "Oh my God, next year the person next to me will be gone," and I did not know what to do anymore. (L233-235; first interview)

Later, Mrs. O's husband reassured her, "Don't worry, I'll make sure you survive," <a husband's thoughts that depict the trajectory of only survival>, and she «continued to cleverly and laboriously cook unusual meals». However, when she lost him, «she became hopeless and wanted to reunite with her husband».

Although I knew (my husband) would never show up, I felt, "I do not care if it is another time, just come to my bedside, pull me by the hand and take me to the other side." When my husband died, that was all I could think about, and (omission) I felt that I could never have been as happy as I was in this world without him. (L408-418; first interview)

Her expected loss became a reality with her husband's death, and she had to adjust to a new environment. However, the habits she had before the death continued and were incompatible with the new environment. Mrs. O experienced the following:

Cover My Thoughts and Live with Landmines. I wanted to tell the story from the beginning, but I felt that I could not tell it well and that no one would accept it, so I put a lid on it. (L49-51; second interview)

I call it a "landmine." Even when I am living a normal life and just looking at the blue sky, I suddenly think, "Oh, the sky is so blue, I wish I could have seen it with him." Or when you

Table 3. Category Summary of Growth Trajectory.

Growth Trajectory	Summary
Category I	There were ten relevant participants (B, H, I, J, O, P, Q, S, T, and U). These participants had been challenged about their habits with their spouses before notification, but never questioned their habits before the bereavement and spent their time consciously supporting their spouse's preferred lifestyle. However, when the anticipated loss became a reality and the habits with the living spouse were challenged again, the habits were reorganized by actively living alone, reaffirming the connection with the spouse, and perceiving it as a source of emotional support. The four participants (B, H, J, and U) who fell into this stage had not yet changed their habits at the time of the interview and were not yet compatible with their new environment.
Category 2	There were seven relevant participants (A, C, E, K, M, N, and R), whose habits with their living spouses had been challenged because of bereavement, and the foundation of their existence had been shaken. They challenged their habits of reconstructing their identities to stabilize their shaky foundation of self-reliance and acquired new habits related to their spouses, reaffirming their connection with them, and finding them a source of emotional support. The three participants who fell into this stage (K, N, and R) had not yet reorganized their habits at the time of the interview and were not yet compatible with their new environment.
Category 3	There were four relevant participants (D, F, G, and L), who questioned their habits of building a foundation for independent living because their habits with their spouses before they were informed of their illness and prognosis were challenged when they faced the separation that would occur shortly after they told their spouses of their illness and prognosis while they were alive. In parallel with questioning habits, they found that they were reconnecting with their spouse while supporting their still-living spouse at their side who was struggling with a limited life, and they found this to be a source of emotional support. This connection with their spouse persisted after bereavement, and the habit reorganized shortly after the spouse's death.

see an elderly couple sitting in front of you on the train and think, "Oh, I wish I could have been like them," and I feel envious, I think: ...... (omission) "Oh, I came here with him," and the scene from that time together returns to my mind. Often, I feel like I am squatting down on the spot, gasping for air, thinking, "Oh my God! There is a landmine here today." (L490-497; first interview)

Learning How to Overcome Landmines When Stepping on Them Once I realized that it was okay to feel normal, I began understanding how to get over it. Thus, I think the rock that had been there growing, like a rock that can be moved. I think I can handle it now. But, you know, the depth of grief and the part of stepping on a landmine and not being able to do

anything about it, well, that remains. I think the idea of being able to deal with it, the way I feel about the future, how I deal with it, the idea of being able to do that, I think the stone has become smaller. (L512-518; first interview)

Describe My Experience in Writing. I could speak out a little more to the bereaved association, and I was asked to write a manuscript that was published in the bereaved association's brochure. I was also interviewed for something. As I was talking about it, everything kind of fell into place. (L45-48; second interview)

Immediately after bereavement, Mrs. O wanted to write the story of her life without him, but could not and agreed that she would finish it at this point. However, two years after bereavement, she acquired the habit of accepting her husband's death and actively living her own story, although her feelings were unsettled. Mrs. O began «living happily despite her sadness, with her original character», satisfied with her present self, and adapted to the new environment.

The Loss of His Wife Has Led Him to Hope for a Future Alone, Although He Cannot Accept Who He is Now. Mr. B. lost the married life he had envisioned when he unexpectedly learned that his wife would not live longer.

I never expected my wife to suddenly be diagnosed with cancer and was told that she only had about six months to live. I did not tell my wife that. Well, my wife also felt that she could not go beyond the year since her diagnosis in May. (L130-133; first interview)

After that, <she suddenly became unconscious>, and Mr. B., unable to cope with the changes in her condition, «always stayed by her side» in the hospital room, frightened. After her funeral, Mr. B faced life without her, and consequently «became alone, lonely, and clueless».

I live alone now. Well, I do not know if I would have had children, but I live alone. Hence, it is lonely at night. During the day I go out a little bit, but I wonder about not knowing what to do. (L28-31; first interview)

Mr. B understood that the time he could spend with his wife was short, but the bereavement forced him to face her absence and move to a new environment. However, his habits with his still-living wife continued, and he became incompatible with the new environment. Mr. B experienced the following:

Drown My Loneliness by Visiting Memories of My Wife. I go everywhere to have fun. (omitted) When I have a vacation, I go somewhere else (omitted) I go to those places alone, and this time I retrospect and wander, and do things like that. I liked flowers, hence I went to places to see them. The first year I went everywhere to see flowers, and I walked around all the time. (L51-60; first interview)

Interacting With Friends and Others Associated with My Wife Surprisingly, the people around me took care of me. I had many family members, who helped me a lot. I just got invited to a softball game because they said, "You should not stay home," and now I am playing (laughs). (L76-80; first interview)

Although Mr. B could affirm his connection to his wife and recognize that as a source of emotional support, he had yet to acknowledge his current self by «chanting sutras daily for his wife» and was searching for a self in a new environment that made sense to him. However, Mr. B's belief that < he and his wife are very lucky > led him to «be optimistic for a happy life with his grandchildren, despite loneliness», in the hope that he would continue to be blessed with good fortune.

## Category 2

Mr. M and Mrs. K describe their growth experiences in the same manner as in Category 1.

# He Lives Vicariously Through His Wife, Triggered by His Realization That He Was Not Paying Attention to Her

Mr. M's wife was diagnosed with cancer and continued to fight the disease. He unexpectedly had to care for his wife at home and was shocked at his own inability to understand her wishes.

I think (my wife) already knew that death was approaching. Then, I did not understand that at all. I am completely hopeless about things like that. I cannot think about people's feelings or their pain and suffering at all. So, it was hard. (L301-304; first interview)

At a bereaved association that he attended after his wife's death, he witnessed the reactions of other bereaved families that were different from his own and realized that he had not cared for his wife and had lost confidence in his attitude toward her.

We were not a close couple. (Omission) When I visit the bereaved associations, many people are very shocked. I did not have anything like that. I was kind of shocked at myself in retrospect. (L21-24; first interview)

The loss of confidence in his attitude toward his wife forced Mr. M into a new environment, but his habits toward his still-living wife remained and were incompatible with the new environment. Mr. M experienced the following:

From Repentance Toward Their Wives to a Better Understanding of My Wife. That (the fact that I could only think about myself even though my wife had breast cancer) is the

opposite of, you know, what I should have done at that time, and I am still very sorry. That is what is left now. (L96-98; first interview)

I want to cherish the various influences I received from my wife, though, I cannot catch up with her anymore. (L100-101; first interview)

It is much better to think about what had been most important to my wife and how she had thought about it until the end of her life than to ask other people how we should live our lives. It's much more meaningful for me to think about that, even though I am still detached from my wife, it makes me much happier. I think it makes a lot more sense for me to focus on that. So, I think that is what I want to focus on. (L544-549; first interview)

Live on Through My Wife. After she died, I tried to continue with my life as we both had been doing. Well, my life has not changed much. (L29-31; first interview)

I have been imitating (my wife), uh, for about two years, I have been living alone for a little over two years. (L101-102; first interview)

Through these experiences, Mr. M. questioned his past habits with his still-living wife, reaffirmed his connection to her, realized that this was a source of emotional support, and acquired the habit of maintaining his life with his wife while remembering her and [by imitating his wife and continuing their life together], Mr. M. was convinced and adapted to the new environment.

Admitting to Myself That I Am in a State of Humiliation and Not Growing Because of the Loss of One's Position and Pride. Mrs. K, who had not always discussed and resolved everything together, felt frustrated because she could not tell her husband that she could not treat him, and could not discuss how she and her husband could live while planning for life after his death. Mrs. K lost her pride as the wife of the head of the family because of her husband's death.

My feelings were already mixed up. My position was shaken, my pride was broken.... (omitted) Among my relatives, he was like the head of the family. I thought I had worked a lot with him, but when he died, I thought I would replace him. But when he died, I did not replace him. I am not his heir (omitted), at least the one we thought was the head was my brother, and my pride is shredded now, I worked so hard. (L273 - 283; first interview)

The loss of her position and pride forced Mrs. K. into a new environment, but the habits of her still-living husband's death remained and were incompatible with the new environment. Mrs. K experienced the following:

Understand Her Thoughts and Feelings Toward Her Husband. We could not talk to each other, and then he died, and that is a situation of sadness and grief for him. (L107-108; first interview)

I started thinking, you know, what kind of existence did I have after his death? Yes, I know. It is too lonely to think about him being gone. Yes. And from the Buddhist point of view, I

think he went to paradise, that is the closest thing I can say. He is in paradise living a carefree life. He does not care about me and he does not do anything about it. I do not think he is going to hell. He is probably in paradise. (L456-461; first interview)

Look for Things That Support Me. Anyway, I thought that if I did not talk to someone about the issue (the loss of my husband), I would not be able to hold myself. (L266-267; first interview)

Going to the bereaved association was a great support for me. (L113-114; first interview)

She believes that the reason she could not recover from the loss is "the land problem at home, which she considers the root of all evil." Due to the property issue, Mrs. K was not satisfied with her current situation [she spends the day in a state of depression] and was looking for a new self that she could be satisfied with within a new environment. Additionally, Mrs. K says, "I have not grown up or done anything, I am just exhausted and asleep," suggesting that her thoughts are stuck in the present or past and that she is unable to look forward even if she wants to, while also admitting that she "hasn't grown up." This manifests self-affirmation and a significant change for Mrs. K.

## Category 3

Mrs. L describes her growth experiences in the same manner as in Category 1.

She Did Not Know When Her Husband Would Die and Was Relying on the Deep Bond and Supportive Words with Him and Her Family. When her husband was diagnosed with cancer and was told that he had only a few days to live, Mrs. L. lost faith that he would be there for her and «was put in a situation where she did not know when her husband would die».

I was told clearly from the beginning that he would not survive. They told me that they did not know how long he would live, but that it was short. (L20-21; first interview)

I was a naive person, and suddenly it was clear that my husband would not survive. I had gotten into a situation where I did not know when he was going to die. (L38-39; first interview)

The loss of the certainty that her husband would be by her side forced Mrs. L into a new environment; however, her habits with her husband before the announcement of his illness and prognosis remained and were incompatible with the new environment. Mrs. L experienced the following:

Staying Together as a Family and Remaining Stable When Flying Low. When life is built right, it isvery difficult, you know, it becomes a very unhappy ground for people, but... when you are at the bottom, you are stable in your way. (L112-114; first interview)

It is really that the family has come together, you know. It became the last three months that we have spent together, just the four of us. (L135-136; first interview)

Have the Feeling of Being Simultaneously Sad and Happy. The time of his illness was the most beautiful, purest, happiest, and saddest. But the feeling of happiness and sadness existed simultaneously, that was something I did not realize until I experienced it, you know, there are such strange things. That is still a mystery. (L148-150; first interview)

Using the Deep Bonds I Have Built With my Husband and Family as a Foundation for Living on My Own. While fighting the disease, you usually lose a lot, but although I lost a lot, I also gained a

lot. This is not something I accumulated alone, but mainly because my husband showed me how to live like this. This accumulation, well, also gave me self-confidence. (L237-241; first interview)

In my case, what we all built together fighting the disease, what my husband, I, and the children had built together before we found out about the disease (omitted), the mentality during the disease in our lives, and the buildup, I think that supports the bereaved family after death, well, in our case it did. (L248-255; first interview)

By questioning her habits during her struggle with her husband, Mrs. L reaffirmed her connection to her husband and found this to be a source of emotional support. Shortly after the bereavement, she was convinced of herself «living confidently based on what she had gained» and adapted to the new environment.

#### Discussion

# Summary of the Findings

Despite the differences in the growth experiences of survivors bereaved of a spouse by cancer, there are some common growth patterns. Growth was triggered by questioning their habits with the living spouse. Focusing on the nature of growth experiences helped the participants create new perspectives on growth: 1) growth that begins before the bereavement, 2) impact of the timing of habit reorganization, and 3) affirmation of connection with the spouse and recognizing that as emotional support.

## Discussion of Findings

Growth Beginning Before Bereavement. Participants in Categories one and three suffered bereavement, were forced into a new environment, and had their previous habits

challenged by the disclosure/prognosis of illness to their living spouses. The bereaved family's experiences before and after a loss are often considered separately rather than as a continuum (Broom et al., 2019), and in Tedeschi and Calhoun's growth model of grief, struggling with the trauma of losing a loved one is also a trigger for beginning the growth process (Calhoun et al., 2010). Our findings suggest that a continuous perspective on bereaved families before and after the loss of a patient is necessary to capture their growth because the growth process begins when the living spouse is informed of the prognosis of the disease, which is a novel finding.

Impact of the Timing of Habit Reorganization. The results show three categories of growth trajectories, with some participants in Categories 1 and 2 having reorganized their habits, while others had not developed new habits at the time of the interview. We hypothesized that participants' experiences before bereavement may have made some of them reorganize their habits. Moreover, the timing of habit reorganization is hypothesized to be influenced by growth progression, as Category 3 participants reorganized their habits in a shorter period after bereavement compared to the other participants.

All the participants had experienced pre-loss grief because they had been informed of a diagnosis for their still-living spouse. Those with reorganized habits experienced pre-loss grief but acknowledged the impending loss. Conversely, those whose habits had not been reorganized experienced pre-loss grief, but experienced bereavement without being aware of the impending loss. Caregiving spouses are particularly prone to experiencing higher levels of pre-loss grief associated with negative post-loss outcomes, such as increased depressive symptoms, stress, avoidance, and prolonged grief (Majid & Akande, 2022). However, our findings suggest that rather than pre-loss grief, the ability to be aware of and acknowledge the impending death of the living spouse influences growth.

There is a multidimensional concept of preparedness for death that is distinct from pre-loss grief and includes cognitive, emotional, and behavioral components (Skantharajah et al., 2022). Our results show that compared to other participants, only Category three participants, whose habits were reorganized in a shorter time after bereavement, were prepared for death. This supports the finding that a higher level of perceived preparedness for death is a factor for better adjustment after a loss (Treml et al., 2021). However, the finding that participants in Categories 1 and 2 were not prepared for death confirms previous findings that nearly half of spouse/partner caregivers were emotionally unprepared and 35% were realistically unprepared for death (Majid & Akande, 2022). Nevertheless, our results also showed that, before bereavement, some people are more aware of their closeness to the finite life of their living spouse than they are prepared for death, and they prefer maintaining their relationship with their spouse until their death before the diagnosis is made. A study of cancer patients' caregivers in the six months before death that revealed trends in cognitive (awareness of the patient's chances of recovery) and emotional preparation for death found that approximately 60% of grieving spouses were not adequately

prepared for death (Albuquerque et al., 2018). Bereaved families should therefore not hasten their growth by preparing for death, but rather develop at a pace that matches their steps.

Affirmation of Connection with the Spouse and Recognizing Emotional Support. According to our results, this was an important trigger for habit reorganization. Building and maintaining a bond with the deceased is critical for survivors, and the deceased can be said to be present through objects and activities as survivors continue the bond in various ways to adjust to life after losing their spouse (Sköld, 2021). The integration of the dead with the living through an ongoing bond with the deceased is an important element of bereavement, indicating that grief is not something to be overcome, but to be learned to live with (Sköld, 2021). The respondents in the present study could live with a spouse by absorbing the spouse's presence as emotional support and establishing a connection. Hence, it is important to ask how the bereaved locate their continuing relationship with the deceased in their narrative, what ontological position they assign to the deceased, and why it is important (DeGroot et al., 2019) for growth.

Implications for Practice. Caregivers must think about how caregiving spouses can be involved in the long term to meet their needs, while anticipating what growth trajectory is appropriate for them at the time of cancer diagnosis. Caregivers must support the living patient's families, not only with post-loss grief management but also with preloss grief management and continuing the work with the patient until death. Caregivers must help bereaved families reaffirm their connection to their spouse, find emotional support by repositioning them within themselves, and become comfortable with who they become.

## Strengths and Limitations

Of the 21 participants, 20 were referred by a bereaved association, which may have influenced the results. However, the study's strength is that it focused on survivors' growth experiences from losing a spouse to cancer and analyzed them phenomenologically. Moreover, a new perspective on growth was found using the idea of habit reorganization based on Merleau-Ponty's theory as a philosophical foundation.

## Implications for Clinical Practice

Caregivers must strategize how to meet the long-term needs of bereaved families by anticipating the appropriate growth trajectory for the caregiving spouse at the time of the cancer diagnosis. Additionally, caregivers involved with the family before bereavement must be involved not only to alleviate grief after a bereavement but also to help the patient acknowledge impending death and support the patient until death, despite pre-loss grief. Moreover, caregivers must help survivors reaffirm their connection to their spouse, recognize that repositioning provides emotional support, and be

comfortable with who they are in the present. Specific care methods that support grieving families' growth must be explored.

#### Conclusion

The present phenomenological analysis founds that for survivors, growth "begins when the living spouse is informed of the disease and prognosis," "meaning accompanying the spouse until his or her death and unfolding at their own pace," and "meaning reaffirming the connection with their spouse, realizing that it provides emotional support, and living with their spouse."

## **Acknowledgments**

We would like to express our sincere gratitude to the 21 bereaved families who participated in this research and shared their valuable experiences.

## **Declaration of Conflicting Interests**

The authors declare that they have no potential conflicts of interest related to the research, authorship, or publication of this work.

## **Funding**

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This research was funded by a grant from the Ministry of Education, Culture, Sports, Science and Technology, Grant-in-Aid for Scientific Research (Young Scientists' Research: FY 2018–2020 "Qualitative study on the positive impact of bereavement on bereaved families," PI: Kazuki Shimada, Kyoto University Hospital, 1 8 K 1 5 3 8), a public research fund.

## **Ethical Approval**

The research protocol was approved by the Medical Ethics Committee of a university (Approval number R1932). As narrating bereavement experiences may be painful, participants were offered the option of taking a short break or ending the interview. However, none of the participants exercised it.

#### **ORCID iD**

Megumi Kondo (b) https://orcid.org/0000-0001-5125-8499

#### References

Albuquerque, S., Narciso, I., & Pereira, M. (2018). Posttraumatic growth in bereaved parents: A multidimensional model of associated factors. *Psychological Trauma: Theory, Research, Practice and Policy*, *10*(2), 199–207. https://doi.org/10.1037/tra0000305

Aoyama, M., Sakaguchi, Y., Morita, T., Ogawa, A., Fujisawa, D., Kizawa, Y., Tsuneto, S., Shima, Y., & Miyashita, M. (2018). Factors associated with possible complicated grief and major depressive disorders. *Psycho-Oncology*, 27(3), 915–921. https://doi.org/10.1002/pon.4610

- Arslan, B. S., Özer, Z., & Buldukoğlu, K. (2020). Posttraumatic growth in parentally bereaved children and adolescents: A systematic review. *Death Studies*, 44(1), 111–123. https://doi.org/10.1080/07481187.2020.1716886
- Broom, A., Parker, R. B., & Kenny, K. (2019). Authenticity, ambivalence and recognition in caring at the end of life and beyond. *Social Science and Medicine (1982)*, 239, 112554. https://doi.org/10.1016/j.socscimed.2019.112554.
- Calhoun, L. G., Tedeschi, R. G., Cann, A., & Hanks, E. A. (2010). Positive outcomes following bereavement: Paths to posttraumatic growth. *Psychologica Belgica*, 50(1-2), 125–143. https://doi.org/10.5334/pb-50-1-2-125
- DeGroot, J. M., Klass, D., & Steffen, E. M. (2019). Continuing bonds in bereavement: New directions for research and practice. *Omega (Westport)*, 79(3), 340–342. https://doi.org/10.1177/ 0030222819839801
- Gilmer, M. J., Foster, T. L., Vannatta, K., Barrera, M., Davies, B., Dietrich, M. S., Fairclough, D. L., Grollman, J., & Gerhardt, C. A. (2012). Changes in parents after the death of a child from cancer. *Journal of Pain and Symptom Management*, 44(4), 572–582. https://doi.org/10.1016/j.jpainsymman.2011.10.017
- Giorgi, A. (2009). The descriptive phenomenological method in psychology: A modified husserlian approach. Duquesne University Press.
- Helgeson, V. S., Reynolds, K. A., & Tomich, P. L. (2006). A meta-analytic review of benefit finding and growth. *Journal of Consulting and Clinical Psychology*, 74(5), 797–816. https://doi.org/10.1037/0022-006X.74.5.797
- Hirooka, K., Fukahori, H., Taku, K., Izawa, S., & Ogawa, A. (2019). Posttraumatic growth in bereaved family members of patients with cancer: A qualitative analysis. *Supportive Care in Cancer: Official Journal of the Multinational Association of Supportive Care in Cancer*, 27(4), 1417–1424. https://doi.org/10.1007/s00520-018-4440-6
- Hirooka, K., Fukahori, H., Taku, K., Togari, T., & Ogawa, A. (2017). Quality of death, rumination, and posttraumatic growth among bereaved family members of cancer patients in home palliative care. *Psycho-Oncology*, 26(12), 2168–2174. https://doi.org/10.1002/pon.4446
- Hirooka, K., Fukahori, H., Taku, K., Togari, T., & Ogawa, A. (2018). Examining posttraumatic growth among bereaved family members of patients with cancer who received palliative care at home. *The American Journal of Hospice and Palliative Care*, 35(2), 211–217. https://doi.org/10.1177/1049909117703358
- Irie, W., Shiwaku, H., Taku, K., Suzuki, Y., & Inoue, Y. (2021). Roles of reexamination of core beliefs and rumination in posttraumatic growth among parents of children with cancer: Comparisons with parents of children with chronic disease. *Cancer Nursing*, 44(1), 20–28. https://doi.org/10.1097/NCC.00000000000000731
- Kim, K. H., & Shin, Y. S. (2019). A concept analysis of posttraumatic growth in family caregivers of cancer patients. *Asian Oncology Nursing*, *19*(1), 9–17. https://doi.org/10.5388/aon.2019. 19.1.9

- Lee, E. E., & Lee, S. Y. (2020). Caregiving experiences of Korean family caregivers of cancer patients: An integrative literature review. *Psycho-Oncology*, 29(10), 1486–1503. https://doi. org/10.1002/pon.5498
- Lobb, E. A., Kristjanson, L. J., Aoun, S. M., Monterosso, L., Halkett, G. K. B., & Davies, A. (2010). Predictors of complicated grief: A systematic review of empirical studies. *Death Studies*, 34(8), 673–698. https://doi.org/10.1080/07481187.2010.496686
- López, J., Ortiz, G., & Noriega, C. (2019). Posttraumatic growth in parents of children and adolescents with cancer. *Anales del Sistema Sanitario de Navarra*, 42(3), 325–337. https://doi.org/10.23938/ASSN.0717
- Maciejewski, P. K., Zhang, B., Block, S. D., & Prigerson, H. G. (2007). An empirical examination of the stage theory of grief. *Journal of the American Medical Association*, 297(7), 716–723. https://doi.org/10.1001/jama.297.7.716
- Majid, U., & Akande, A. (2022). Managing anticipatory grief in family and partners: A systematic review and qualitative meta-synthesis. *The Family Journal*, 30(2), 242–249. https://doi.org/10. 1177/10664807211000715
- Merleau-Ponty, M. (2012). Phénoménologie de la perception of Perception (Donald A. Landes, Trans.). London and New York: Routledge, Ltd. Press. (Original work published 1945)
- Miyajima, K., Fujisawa, D., Yoshimura, K., Ito, M., Nakajima, S., Shirahase, J., Mimura, M., & Miyashita, M. (2014). Association between quality of end-of-life care and possible complicated grief among bereaved family members. *Journal of Palliative Medicine*, 17(9), 1025–1031. https://doi.org/10.1089/jpm.2013.0552
- Neimeyer, R. A. (2001). The language of loss: Grief therapy as a process of meaning reconstruction. In R. A. Neimeyer (Ed), *Meaning reconstruction and the experience of loss* (pp. 269–292). American Psychological Association.
- Nouzari, R., Najafi, S. S., & Momennasab, M. (2019). Post-traumatic growth among family caregivers of cancer patients and its association with social support and hope. *International Journal of Community Based Nursing and Midwifery*, 7(4), 319–328. https://doi.org/10.30476/IJCBNM.2019.73959.0
- O'Brien, B. C., Harris, I. B., Beckman, T. J., Reed, D. A., & Cook, D. A. (2014). Standards for reporting qualitative research: A synthesis of recommendations. *Academic Medicine: Journal of* the Association of American Medical Colleges, 89(9), 1245–1251. https://doi.org/10.1097/ ACM.00000000000000388
- Schaefer, J. A., & Moos, R. H. (1992). Life crises, and personal growth. In B. N. Carpenter (Ed), *Personal coping: Theory, research, and application* (pp. 149–170). ABC-CLIO.
- Silva, D. M. D., Silva, R. M. C. R. A., Pereira, E. R., Ferreira, H. C., Alcantara, V. C. G. D., & Oliveira, F. D. S. (2018). The body marked by the arteriovenous fistula: A phenomenological point of view. *Revista Brasileira de Enfermagem*, 71(6), 2869–2875. https://doi.org/10.1590/0034-7167-2017-0898
- Skantharajah, N., Barrie, C., Baxter, S., Carolina Borja, M., Butters, A., Dudgeon, D., Haque, A., Mahmood, I., Mirhosseini, M., Mirza, R. M., Ankita, A., Thrower, C., Vadeboncoeur, C., Wan, A., & Klinger, C. A. (2022). The grief and bereavement experiences of informal caregivers: A scoping review of the north American literature. *Journal of Palliative Care*, 37(2), 242–258. https://doi.org/10.1177/08258597211052269

Sköld, A. B. (2021). A hopeless search for the hopeless: A literature review of contemporary qualitative studies on partner bereavement. *Human Arenas*, 4(4), 518–541. https://doi.org/10.1007/s42087-020-00122-w

- Slaughter, R. I., Hamilton, A. S., Cederbaum, J. A., Unger, J. B., Baezconde-Garbanati, L., & Milam, J. E. (2020). Relationships between parent and adolescent/young adult mental health among hispanic and non-hispanic childhood cancer survivors. *Journal of Psychosocial Oncology*, 38(6), 746–760. https://doi.org/10.1080/07347332.2020.1815924
- Stroebe, M., Schut, H., & Finkenauer, C. (2001). The traumatization of grief: A conceptual framework for understanding the trauma-bereavement interface. *The Israel Journal of Psychiatry and Related Sciences*, 38(3-4), 185–201.
- Taku, K., Calhoun, L. G., Tedeschi, R. G., Gil-Rivas, V., Kilmer, R. P., & Cann, A. (2007).
  Examining posttraumatic growth among Japanese university students. *Anxiety, Stress, and Coping*, 20(4), 353–367. https://doi.org/10.1080/10615800701295007
- Tang, F. W. K., & Lee, D. T. F. (2017). A phenomenological study of hospital readmissions of Chinese older people with COPD. *The Gerontologist*, 57(6), 1113–1122. https://doi.org/10.1093/geront/gnw134
- Tedeschi, R. G., & Calhoun, L. G. (1995). *Trauma and transformation: Growing in the aftermath of suffering* (pp. 29–88). SAGE Publications.
- Tedeschi, R. G., & Calhoun, L. G. (1996). The posttraumatic growth inventory: Measuring the positive legacy of trauma. *Journal of Traumatic Stress*, 9(3), 455–471. https://doi.org/10.1007/BF02103658
- Tedeschi, R. G., & Calhoun, L. G. (2004). Target article: Posttraumatic growth: Conceptual foundations and empirical evidence. *Psychological Inquiry*, *15*(1), 1–18. https://doi.org/10.1207/s15327965pli1501\_01
- Tedeschi, R. G., & Calhoun, L. G. (2008). Beyond the concept of recovery: Growth and the experience of loss. *Death Studies*, 32(1), 27–39. https://doi.org/10.1080/07481180701741251
- Tedeschi, R. G., Park, C. L., & Calhoun, L. G. (1998). Posttraumatic growth: Conceptual issues. In R. G. Tedeschi, C. L. Park, & L. G. Calhoun (Eds), *Posttraumatic growth: Positive changes in the aftermath of crisis* (pp. 1–22). Lawrence Erlbaum Associates.
- Toombs, S. K. (Ed), (2001). Introduction: Phenomenology and medicine. *Handbook of phenomenology and medicine* (pp. 3–26). Kluwer Academic Publishers.
- Treml, J., Schmidt, V., Nagl, M., & Kersting, A. (2021). Pre-loss grief and preparedness for death among caregivers of terminally ill cancer patients: A systematic review. *Social Science and Medicine* (1982), 284, 114240. https://doi.org/10.1016/j.socscimed.2021.114240
- Yopp, J. M., Deal, A. M., Nakamura, Z. M., Park, E. M., Edwards, T., Wilson, D. R., Biesecker, B., & Rosenstein, D. L. (2019). Psychological and parental functioning of widowed fathers: The first two years. *Journal of Family Psychology: JFP: Journal of the Division of Family Psychology of the American Psychological Association (Division 43)*, 33(5), 565–574. https://doi.org/10.1037/fam0000528

## **Author Biographies**

**Megumi Kondo**, MS, obtained her Department of Human Health Sciences degree at the Kyoto University Graduate School of Medicine. She has been caring for cancer patients as a nurse and is presently engaged in research on grief care in the doctoral program at the Kyoto University Graduate School of Medicine.

**Tomoki Kihira**, PhD obtained his postgraduate degree at Osaka University. He joined the College of Nursing Art and Science, University of Hyogo as a Professor of Philosophy.

**Dr. Yukihiro Sakaguchi**, is a professor of Thanatology and a director of the Research Center for Grief and Bereavement, at Kwansei Gakuin University. He received a PhD in Human Sciences from Osaka University, Japan, in 2001. He is editor-in-chief of the Japanese Journal of Grief and Bereavement Research. His research interests include loss, grief, and bereavement care. He was a member of a working group that developed the first Japanese evidence-based clinical practice guidelines for the care of psychologically distressed bereaved families in 2022.

**Kazuki Shimada**, MD, PhD, obtained his PhD in Medicine, at the University of Osaka. He joins Kyoto University Hospital as a senior lecturer for the Department of Palliative Medicine.

**Yuki Shirai**, PhD, obtained her degree in Philosophy of Health Sciences, at the University of Tokyo. She has been at Kyoto University for 6 years and is an Associate Professor of Palliative Nursing in course of Advanced Nursing Sciences.

**Dr. Keiko Tamura**, RN, PhD, OCNS, is a professor at the Department of Palliative Nursing, Graduate School of Medicine, Kyoto University. She received a PhD in Medicine from Osaka University. She obtained her certification as an oncology clinical nurse specialist and has been practicing hospice and palliative care for cancer patients and their families. She also conducts research on spiritual care and nurse education programs.