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Posttraumatic growth and death anxiety in caregivers of cancer patients: PHOENIX study

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1. Introduction
Caregiving a loved one diagnosed with cancer involves providing important emotional, practical, and physical care. However, it is a complex and sometimes overwhelming task. The caregivers of cancer patients (CCPs) are exposed to psychosocial and physical problems, e.g., psychological distress, a decrease in quality of life, and lack of satisfaction in relationships. However, people facing highly stressful life events such as cancer may experience both negative and positive outcomes [1].

Posttraumatic growth (PTG) is defined as positive psychological changes that occur following a meaningfully challenging or traumatic life event [2]. After a traumatic event, an individual's assumptions about the world, themselves, and others are damaged. This change causes a reevaluation and rebuilding of belief systems [3]. A diagnosis of cancer and its consequences may become a series of traumas for CCPs. However, it is hypothesized that CCPs may experience positive changes, e.g., closer relationships with others, a greater appreciation of life, clarification of life priorities, increased faith, and more empathy for others [4]. The factors influencing PTG in CCPs are social support, quality of the spousal relationship, spouse's PTG, younger age, intrusive thoughts, and marital satisfaction; there is an increase in PTG with shorter diagnosis periods [5,6].

Death anxiety (DAN) is a group of psychological reactions originating from the idea that the self does not exist [7]. The presence of an incurable disease and conscious awareness of mortality can promote DAN [8]. Death anxiety causes a decrease in quality of life, both in patients and CCPs [9,10].

In the literature, PTG has been studied from different perspectives, and there are different models to explain its
obtained from medical reports. The attending physician's diagnosis, time to follow-up, and disease status were parameters, information regarding patient age, primary history of psychiatric admissions. In addition to background (presence of siblings, monthly household collected demographic data, information on sociocultural evaluated using face-to-face interviews. The questionnaires structured questionnaires; illiterate individuals were as illiterate/literate versus additional education. up time (6 months), and educational status was analyzed average wage in Turkey (i.e. 2000 TL) and divided into low income parameters were grouped according to the median age of participants were grouped according to the median age that impeded participation in the palliative care. Those with a history of cancer or disease, we included the relatives of patients in remission, of all clinics that cared for patients over 16 years of age were included. The study was held in outpatient clinics were evaluated. Individuals who were ≥18 years of age were included. The study was held in outpatient clinics that cared for patients over 16 years of age with all types of cancers at any stage. To evaluate the effects of the disease, we included the relatives of patients in remission, patients undergoing adjuvant or palliative therapy, and in those in palliative care. Those with a history of cancer or neuropsychiatric illness that impeded participation in the survey were excluded. During statistical analysis the ages of participants were grouped according to the median age of 40. Income parameters were grouped according to the average wage in Turkey (i.e. 2000 TL) and divided into low or high income. In addition, the length of follow-up was divided into long or short according to the median follow-up time (6 months), and educational status was analyzed as illiterate/literate versus additional education.

The caregivers of cancer patients were evaluated using structured questionnaires; illiterate individuals were evaluated using face-to-face interviews. The questionnaires collected demographic data, information on sociocultural background (presence of siblings, monthly household income, etc.), comorbidities, educational status, job status, and history of psychiatric admissions. In addition to evaluating the effects of patient characteristics on caregiver parameters, information regarding patient age, primary diagnosis, time to follow-up, and disease status was obtained from medical reports. The attending physician recorded the relation of the participant. Participants were asked about their attitude towards screening tests after the cancer diagnosis of their loved ones. Additionally, a question asking them to score the impact of the diagnosis on daily life was added; participants were asked to score according to the Likert scale (very low, low, moderate, high, and very high). Scores of high and very high were analyzed as a high level of impact. To assess DAN and PTG, the validated PTG scale and Templer DAN scale were used. The validity and reliability of the Turkish version have been tested by Senol et al. [14] and Akça et al. [15]. These studies demonstrated test–retest reliability of \( r = 0.86 \) (\( P < 0.001 \)) and 0.79, respectively. The death anxiety scale consists of 15 items, self-report, and a 2 point Likert instrument. The statements are assessed as wrong and right and scored as 0 and 1, respectively. The sum of the 15 items results in a score ranging from 0–15. Scores ≥7 are defined as high DAN. Assessment of PTG was performed by PTG inventory [2]. The psychometric properties of the inventory have been tested in the Turkish population by Dirik et al. [16] and Kağan et al. [17]. Both analyses showed the validity and reliability of the test in Turkish individuals. The instrument includes 21 items rated on a 6 point Likert scale (0–5). The sum of the 21 items results in a score ranging 0–105. Higher scores mean positive psychological changes due to adverse life events. There are subscales of the inventory to evaluate growth in self-perception, philosophy of life, and changes in relationships. In the current analysis, the median score of the PTG scale (70.0) was used to group PTG into high and low.

2. Materials and methods
The study was designed as a multicenter survey and was conducted in 3 cancer centers in Turkey. An institutional ethics committee approved the study protocol, and the study was carried out following the ethical standards of the 1964 Declaration of Helsinki. All the participants signed informed consent.

The caregivers of cancer patients admitted to outpatient clinics were evaluated. Individuals who were ≥18 years of age were included. The study was held in outpatient clinics that cared for patients over 16 years of age with all types of cancers at any stage. To evaluate the effects of the disease, we included the relatives of patients in remission, patients undergoing adjuvant or palliative therapy, and in those in palliative care. Those with a history of cancer or neuropsychiatric illness that impeded participation in the survey were excluded. During statistical analysis the ages of participants were grouped according to the median age of 40. Income parameters were grouped according to the average wage in Turkey (i.e. 2000 TL) and divided into low or high income. In addition, the length of follow-up was divided into long or short according to the median follow-up time (6 months), and educational status was analyzed as illiterate/literate versus additional education.

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2.1. Statistical analysis
Baseline characteristics of the patient group were described by using frequencies and proportions for dichotomous and categorical variables. Univariate analysis of the predictors of high DAN and PTG scores was performed by chi-square or Fisher exact tests. Parameters with a P-value less than 0.10 were further analyzed in multivariate analysis. Using a logistic regression model, several parameters were further tested for PTG in multivariate analysis. These included being a spouse, being over 40 years of age, being married, female sex, siblings, and high DAN scores. For DAN, caring for elderly patients, female sex, siblings, low income, not working, the presence of chronic disease, history of psychiatric admission, and high PTG scores were analyzed. The correlation between PTG and DAN was tested using the Pearson correlation coefficient. All analyses were performed using SPSS 17.0 for Windows (SPSS Inc., Chicago, IL, USA), and P-values below 0.05 were considered statistically significant.

3. Results
Between August 2017 and April 2018, 426 participants were evaluated in 3 different cancer centers. The median age was 40.5 years (17–70), and 50.2% were female (Table 1);
58.9% were 1st-degree relatives, and 61.7% were living in the same house. One hundred ninety-five patients (45.8%) were more than 65 years of age, and most diagnoses were gastrointestinal (29.3%) and breast (23.9%) cancers (Table 2). Among the patients, 240 (56.3%) were under palliative chemotherapy or radiotherapy. Three hundred sixty-one participants (84.7%) declared that the diagnosis had a high level of impact on their daily lives. In addition, 26.1% of participants had a screening for malignancy after the diagnosis of their relative.

The median PTG score was 70.0 (5.0–105.0), and 210 (49.3%) participants had high level PTG scores according to our definition (PTG score ≥70.0). In the univariate analysis, being the spouse of the patient, being over 40 years of age, female sex, being married, siblings, and high DAN scores were associated with high PTG scores (Table 3). In multivariate analysis, a high DAN score was the only parameter associated with high PTG scores [OR: 1.6, CI (95%) 1.02–2.5, P = 0.03] (Table 4). The median DAN score was 8.0 (1.0–14.0), and 311 (73%) participants had high level DAN scores according to our definition (DAN score ≥7). Caring for elderly patients, female sex, siblings, low income, not working, and a history of psychiatric admission were associated with high DAN scores (Table 3). In multivariate analysis, female sex was the only risk factor for high DAN scores [OR: 1.6, CI (95%) 1.1–2.8, P = 0.049] (Table 4). There was a positive correlation between PTG and DAN scores (r = 0.15, P = 0.001). In addition, higher DAN scores were associated with a positive impact on self-perception (37.0 versus 35.0, P = 0.02), philosophy of life (16.0 versus 13.0, P = 0.035), and changes in relationship (16.0 versus 14.0, P = 0.01).

### Table 1. Characteristics of participants.

| Characteristics                          | n(%)     |
|-----------------------------------------|----------|
| Age (median/range)                      | 40.5(17–70) |
| More than 40                            | 213(50.0) |
| Female                                  | 214(50.2) |
| Marital status                          |          |
| Married                                 | 322(75.6) |
| Single/divorced                         | 104(24.4) |
| Children present                        | 316(74.2) |
| Live in                                 |          |
| City center                             | 287(67.4) |
| Town/village                            | 139(32.6) |
| Live in                                 |          |
| Self contained house                    | 191(44.8) |
| Apartment                               | 235(55.2) |
| Monthly income                          |          |
| <1000 TL                                | 77(18.1) |
| 1000–2000 TL                            | 146(34.3) |
| 2000–4000 TL                            | 141(33.1) |
| >4000 TL                                | 62(14.6) |
| Low income (<2000 TL)                   | 223(52.3) |
| Education                               |          |
| Illiterate/literate                     | 33(7.7)  |
| More                                     | 393(92.3) |
| Job                                      |          |
| Retired                                 | 50(11.7) |
| Working                                 | 171(40.1) |
| Not working                             | 205(48.2) |
| Chronic disease present                 | 137(32.2) |
| History of psychiatry admission         | 82(19.2) |
| Degree of relationship                  |          |
| Spouse                                  | 93(21.8) |
| 1st degree                              | 249(58.9) |
| 2nd degree                              | 67(15.7) |
| 3rd degree                              | 17(4.0)  |
| Living in the same house                | 263(61.7) |

### Table 2. Patient characteristics.

| Characteristics                          | n(%)     |
|-----------------------------------------|----------|
| Age (median/range)                      | 63(19–86) |
| Diagnosis                               |          |
| Gastrointestinal cancer                 | 125(29.3) |
| Breast cancer                           | 102(23.9) |
| Lung cancer                             | 61(14.3)  |
| Gynecological cancer                    | 48(11.3)  |
| Prostate cancer                         | 40(9.4)   |
| Others                                  | 50(11.7)  |
| Time to follow-up, months (median/range)| 6 (1–274) |
| Disease status                          |          |
| Remission/follow up                     | 69(16.2)  |
| Under adjuvant therapy                  | 79(18.5)  |
| Palliative chemotherapy or radiotherapy | 240(56.3) |
| Palliative care                         | 38(8.9)   |

4. Discussion

In this study, we tried to look at the positive impacts of a cancer diagnosis on CCPs and planned to analyze the predictors of PTG and DAN. We concluded that high DAN was associated with higher PTG scores, and the female sex was an important factor in death anxiety. We found a statistically significant correlation between PTG and DAN scores.
Table 3. Factors associated with high PTG and DAN scores.

| Characteristics                        | High PTG score | P     | High DAN score (n, %) | P     |
|----------------------------------------|----------------|-------|-----------------------|-------|
| (n, %)                                 | 85(49.4)       | 0.52  | 129(75.0)             | 0.25  |
|                                        | 125(49.2)      |       | 182(71.7)             |       |
| Patient age, years                     |                |       |                       |       |
| <65                                    | 109(47.2)      | 0.20  | 160(69.3)             | 0.03  |
| <65                                    | 101(51.8)      |       | 151(77.4)             |       |
| Disease status                         |                |       |                       |       |
| Remission/follow-up                    | 37(53.6)       | 0.33  | 49(71.0)              | 0.76  |
| Under adjuvant therapy                 | 35(44.3)       |       | 55(69.6)              |       |
| Palliative chemotherapy or radiotherapy| 115(47.9)      |       | 180(75.0)             |       |
| Palliative care                        | 23(60.5)       |       | 27(71.1)              |       |
| Degree of relationship                 |                |       |                       |       |
| Spouse                                 | 55(59.1)       |       | 73(78.5)              |       |
| 1st degree                             | 122(49.0)      |       | 180(72.3)             |       |
| 2nd degree                             | 26(38.8)       | 0.07  | 44(65.7)              | 0.25  |
| 3rd degree                             | 7(41.2)        |       | 14(82.4)              |       |
| Spouse                                 | 55(59.1)       |       | 73(78.5)              |       |
| Other                                  | 155(46.5)      | 0.021 | 238(71.5)             | 0.11  |
| Living in                              |                |       |                       |       |
| Same house                             | 127(48.3)      | 0.33  | 189(71.9)             | 0.28  |
| Another house                          | 83(50.9)       |       | 122(74.8)             |       |
| Age of the participant                 |                |       |                       |       |
| <40                                    | 95(44.6)       | 0.03  | 159(74.6)             | 0.25  |
| <40                                    | 115(54.0)      |       | 152(71.4)             |       |
| Sex                                    |                |       |                       |       |
| Female                                 | 118(55.1)      | 0.01  | 174(81.3)             | <0.001|
| Male                                   | 92(44.4)       |       | 137(64.6)             |       |
| Marital status                         |                |       |                       |       |
| Married                                | 173(53.7)      | 0.001 | 239(74.2)             | 0.19  |
| Single/divorced                        | 37(35.6)       |       | 72(69.2)              |       |
| Sibling                                |                |       |                       |       |
| Present                                | 172(54.4)      | <0.001| 240(75.9)             | 0.01  |
| Absent                                 | 38(34.5)       |       | 71(64.5)              |       |
| Living in                              |                |       |                       |       |
| City center                            | 141(49.1)      | 0.50  | 206(71.8)             | 0.24  |
| Town/village                           | 69(49.6)       |       | 105(75.5)             |       |
| Living in                              |                |       |                       |       |
| Self contained house                   | 98(51.3)       | 0.25  | 141(73.8)             | 0.40  |
| Apartment                              | 112(47.7)      |       | 170(72.3)             |       |
| Monthly income                         |                |       |                       |       |
| Low (<2000 TL)                         | 116(52.0)      | 0.14  | 172(77.1)             | 0.02  |
| High (>2000 TL)                        | 94(46.3)       |       | 139(68.5)             |       |
| Education                              |                |       |                       |       |
| Illiterate/literate                    | 17(51.5)       | 0.46  | 27(81.8)              | 0.16  |
| More                                   | 193(49.1)      |       | 284(72.3)             |       |
| Job                                    |                |       |                       |       |
| Retired                                | 25(50.5)       |       | 31(62.0)              |       |
| Working                                | 77(45.0)       |       | 167(81.5)             | 0.001 |
| Not working                            | 108(52.7)      | 0.33  | 167(81.5)             |       |
| Other                                  |                |       | 144(65.3)             | <0.001|


in their perceptions of themselves, relationships with others, or philosophy of life following their struggle with a major life crisis such as cancer [1]. In addition, PTG has been related to increased self-confidence, the ability to appreciate the present, increased emphasis on family, improved relationships, recognition of new possibilities, and religious growth [19,20]. Although the literature has mostly focused on PTG after the death of cancer patients, a diagnosis of cancer, treatment-related complications, and end of life issues are devastating traumas for CCPs. Female CCPs, older relatives, and those with religious beliefs were reported to have more PTG. Additionally, being the spouse of a cancer patient had positive impacts on spiritual changes [21]. Similar to our results, there are studies in which analysis of sex effects did not yield significant differences [22,23]. In our analysis, participants who were over 40, married, and had siblings were found to have higher PTG, but this was statistically insignificant in multivariate analysis. Balfe et al. studied PTG in caregivers of head and neck cancer patients and showed that increased social support, increasing time since diagnosis, increased worry about cancer, and increased financial stress were associated with more PTG [24]. Ho et al. reported more PTG among those with higher income levels. We could not find any effect of household income and time to follow-up.

Death anxiety originates from the fear of one’s own death and the dying process. Death anxiety is accepted as an important psychological phenomenon that can damage
quality of life [9,10]. Caring for cancer patients may evoke thoughts and fears about personal mortality. Also, CCPs with DAN are prone to increased stress levels, depressive symptoms, and decreased quality of life [25,26]. Female gender and poverty have been associated with higher DAN [10, 27]. In addition, having children, changes in physical appearance, pain, low self-esteem, and physical symptoms have been associated with increased DAN [28].

Consistent with the literature, we found that female sex is an important risk factor for increased DAN in CCPs. There is limited data addressing whether DAN has a positive impact on our lives. However, as discussed by Irvin D. Yalom, once we confront our mortality, we are inspired to rearrange our priorities, communicate more deeply with those we love, appreciate more keenly the beauty of life, and increase our willingness to take the risks necessary for personal fulfillment. Facing death and overcoming the terror of death can make individuals stare at the sun [29]. Ens et al. reported a positive correlation between DAN and personal growth [30]. There is data supporting the negative effects of worrying about cancer and the fear of recurrence in CCPs [31,32] in terms of psychological morbidity and quality of life. Balfe et al. demonstrated a 7.2-fold increase in the benefit of PTG in CCPs suffering from worry about cancer [24]. Consistent with their data, we demonstrated a 1.6-fold increase in the benefit of PTG in CCPs with DAN. Consistent with our results, Gunst et al. demonstrated a positive impact deriving from fear of death on PTG in adolescent cancer patients [12]. The positive effects of DAN on PTG should be further studied. Religiosity and spirituality are important for coping with the psychological trauma caused by cancer [33]. The data about religious beliefs and DAN is limited. However, religious coping plays an important role for CCPs [10]. Bachner et al. found that religious CCPs experienced more DAN [34]. The association between DAN and PTG should be evaluated based on religiosity and spirituality.

This study has some inevitable limitations. Firstly, because it is a survey study, there is an unavoidable subjectivity. The population studied in 3 different cancer centers had a heterogeneous socioeconomic background. In addition, we included relatives up to the 3rd degree to evaluate the effects of close relations. However, studying a specific group of relatives can produce more specific results. The CCPs group was young, with a median age of 40. As a result there could be limitations to the analysis of age as the determinant of DAN and PTG.

In conclusion; in our study, the female sex was found to be an important risk factor for death anxiety. We found a positive impact of death anxiety on positive psychological changes in CCPs. This is the first indication of the association between DAN and PTG in CCPs. This association should be further studied, including spiritual experiences, religious perspectives, and family relations.

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Conflict of Interest
There is no conflict of interest.

Informed Consent
The study protocol received institutional review board approval (Çukurova University School of Medicine, Noninterventional Clinical Studies Review Board; date: 13/04/2018, meeting: 76, decision no: 39), and all participants provided informed consent in the format required by the relevant authorities and/or boards.

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