Posttraumatic growth in palliative care patients and its associations with psychological distress and quality of life

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Abstract

Objectives. Posttraumatic growth (PTG) refers to positive psychological changes resulting from individuals’ inner struggles with traumatic events such as life-threatening illness. Although palliative care patients are confronted with their own mortality, little is known about their PTG experience. This study investigates whether PTG is an empirically relevant concept for palliative patients by assessing the prevalence and areas of growth, and examining associations with psychological distress and quality of life.

Methods. Participants were recruited in Switzerland. Using validated questionnaires, we assessed PTG (Posttraumatic Growth Inventory, PTGI), psychological distress (Hospital Anxiety and Depression Scale), and quality of life (McGill-Quality of Life Questionnaire – Revised). We performed descriptive analyses, Spearman correlations, and linear regressions.

Results. Fifty-five patients completed the PTGI, 44% of whom experienced no/low growth, 47% moderate growth, and 9% high/very high growth. Participants experienced the greatest positive changes in terms of appreciating life and relating to others. We found significant negative bivariate correlations between PTG and psychological distress ($r = -0.33$) and between PTG and depression ($r = -0.47$). Linear regressions showed that PTG is associated with depression ($\beta = -0.468; p = 0.000$), but not with anxiety or quality of life (adjusted $R^2 = 0.219$).

Significance of results. Over half of our patients experienced moderate to very high growth, indicating that PTG is an empirically relevant psychological process in palliative care. PTG is associated with lower levels of depression, possibly as those experiencing growth are more able to process past traumas and build a more positive outlook on one’s life and self. By contrast, the relative independence of anxiety and PTG points to the likely coexistence of positive and negative psychological responses to trauma. The lack of association between PTG and quality of life points to the uniqueness of the PTG concept in capturing how people access deeper meaning and greater appreciation of life along the path toward posttraumatic self-reconstruction.

Introduction

In the mid-1990s, the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders introduced serious illness as a potential traumatic stressor. The announcement of a life-threatening diagnosis, painful experiences, debilitating treatment side-effects and the knowledge of a poor prognosis can indeed be experienced as traumas, understood here as “life-altering” events that deeply challenge, even “shatter” people’s sense of self and core beliefs (Janoff-Bulman, 1992; World Health Organization, 1992; Mundy and Baum, 2004; Cordova et al., 2017; Tedeschi et al., 2018). While illness-related traumas differ from those induced by natural or man-made disasters, insofar as they can be internal and repeated (multiple chronic stressors), empirical research suggests that individuals are likely to experience major psychological changes, whether negative or positive, in response to the trauma of illness (Sumalla et al., 2009; Swartzman et al., 2017).

People with long-term illnesses are estimated to be two to three times more likely to experience psychological distress or mental health issues than the general population (Naylor et al., 2012). Recent studies suggest that one in two cancer patients experiences high levels of psychological distress, and that up to a third of cancer patients or survivors experience posttraumatic stress disorder (Abby et al., 2015; Arnaboldi et al., 2017; Swartzman et al., 2017; Mehnert et al., 2018). Similarly, posttraumatic disorders affect between 9% and 27% of intensive care survivors (Jones et al., 2007; Battle et al., 2017; Hatch et al., 2018; Askari Hosseini et al., 2021), and up to 74% of people with HIV (Sherr et al., 2011).

Overtime, the inner battles and struggles following trauma may instigate a process of transformative, positive psychological changes known as posttraumatic growth or PTG (Joseph and
Linley, 2005; Calhoun and Tedeschi, 2013). In PTG theory, these changes may unfold in individuals’ sense of personal strength, how they relate to others, their openness to new possibilities in life, their appreciation of life, and their spirituality. To measure these, PTG theorists have developed the Posttraumatic Growth Inventory (PTGI), which assesses changes in the five domains above and is, to date, the most common measure of growth. Studies using the PTGI indicate that growth is an important process for people with serious illness. For instance, between 10% and 73% of cancer patients experience moderate to high growth, as do 47% of heart disease survivors (Bluvstein et al., 2013; Wu et al., 2019).

Although PTG is understood as a process of positive cognitive and emotional transformation whereby individuals give deeper meaning and gain greater appreciation of life, rebuilding the shattered self entails sustained, confronting, difficult, and potentially distressing self-reflection (Stockton et al., 2011; Joseph et al., 2012). As such, PTG theory posits that positive and negative psychological responses to trauma are likely to coexist, and that some forms of distress may even act as “catalysts” for growth (Calhoun and Tedeschi, 1998). Such insight may explain inconsistent empirical links between PTG, psychological distress, and quality of life (Tanyi et al., 2020). Reviews reveal contrasting results between distress and growth: a negative association between PTG and posttraumatic stress disorder and depression for people with HIV (Rzeszutek and Gruszczynska, 2018), but a positive one between PTG and stress for cancer patients (Marziliano et al., 2020), for instance. Similarly, empirical studies suggest that the relationship between PTG and quality of life is complex and still ill-understood in people with serious illness — with results encompassing positive, negative, null, and curvilinear relations (Tomich and Helgeson, 2012).

In the posttraumatic stress and growth literature, more acutely perceived threats have been associated with heightened psychological responses, whether positive or negative (Gordova et al., 2001; Holbrook et al., 2001). As highlighted in a meta-analysis, stage 4 cancer patients experienced stronger positive links between posttraumatic stress and growth than less advanced patients, which led the authors to postulate that “the more an event is perceived as threatening […] the more entrenched one will become in the rapid, cyclical process of growth and stress, leading to a stronger relationship between the two constructs” (Marziliano et al., 2020). Against this backdrop, palliative care emerges as a particularly relevant setting to investigate PTG, as patients are likely to experience a heightened sense of vulnerability, being directly confronted with the threat of impending death (Casellas-Grau et al., 2017).

To our knowledge, only two studies have focused on PTG in palliative care patients. One highlights positive links between growth and end of life dreams and visions (Levy et al., 2020). The other, conducted by our research team, found positive associations between gratitude and growth (Althaus et al., 2018). However, key questions of PTG prevalence and associations with psychological distress and quality of life in palliative patients remain unanswered.

To fill this gap, this study investigates whether PTG is an empirically relevant concept for palliative care patients. To do so, we first assess PTG in palliative patients, in terms of prevalence and specific areas of growth. We then investigate associations between PTG and (i) psychological distress, exploring whether people faced with the heightened threat of advanced illness might experience co-occurring growth and distress; and (ii) quality of life, the most important outcome in palliative care, whose links with PTG in those with serious illness are still ill-understood.

**Methods**

This cross-sectional study deployed standardized, validated questionnaires to collect quantitative data about palliative care patients, as part of a wider research project examining gratitude at the end of life (Althaus et al., 2018).

**Procedure and participants**

This study was conducted at the Lausanne University Hospital, Switzerland. It was approved by the hospital’s ethics committee. Recruitment took place between March 2015 and January 2016 at the palliative and supportive care service, which includes an inpatient unit, a consult team, a home care team, and an outpatient clinic. The palliative care team systematically identified eligible individuals, namely palliative care patients over 18 treated for a progressive disease reducing their life expectancy, who had been clinically stable for the past 24 h. People with cognitive or psychiatric disorders impairing their decision-making capacity and those with important communication issues were excluded. A researcher (independent from the healthcare team) visited eligible patients who agreed to be contacted for this study and informed them orally and in writing. She collected the written consent of those who agreed to participate and administered standardized questionnaires in face-to-face interviews.

**Measures**

**Socio-demographic and medical assessments**

We collected socio-demographic data on age, sex, nationality, mother tongue, civil status, education level, and occupation through face-to-face interviews. The healthcare team provided us with patients’ medical data, namely main diagnosis and health status assessed through the ECOG (Eastern Cooperative Oncology Group) Scale of Performance Status, which describes patients’ levels of functioning and autonomy in their daily activities and physical abilities — between 0 (“Fully active, able to carry on all pre-disease performance without restriction”) and 5 (“death”).

**Posttraumatic growth: Posttraumatic Growth Inventory (PTGI)**

The PTGI consists of 21 items that each describe a potential change caused by a trauma on a 6-point Likert scale, between 0 (“I did not experience this change as a result of my crisis”) and 5 (“I experienced this change to a very great degree as a result of my crisis”) (Tedeschi and Calhoun, 1996). The questionnaire yields a total score ($\alpha = 0.89$) and intermediate scores in five subscales: “relating to others” ($\alpha = 0.78$), “new possibilities” ($\alpha = 0.73$), “personal strength” ($\alpha = 0.77$), “spiritual change” ($\alpha = 0.61$), and “appreciation of life” ($\alpha = 0.61$). Higher scores reflect higher levels of PTG. We used a validated French translation of the questionnaire (Lelorain et al., 2010).

The PTGI is not a diagnostic instrument and lacks established cutoffs and reporting standards (Wu et al., 2019). To examine and describe the levels of PTG experienced by our participants, we drew inspiration from a study on PTG in cancer survivors (Jansen et al., 2011) and differentiated between no growth or low growth, moderate growth, and high to very high growth, as...
outlined in Table 1. Prior to administering the PTGI, we also sought to mitigate potential positivity bias by assessing overall, negative and positive subjective changes linked with the illness — through the questions: “Globally, to what extent would you say that your illness has negatively (Q1)/positively (Q2) changed your personality and/or your life?” (0–10).

Quality of life: McGill Quality of Life Questionnaire – Revised (MQoL-r)
The 14-item questionnaire assesses the quality of life of people with life-threatening illnesses (Cohen et al., 2017). It yields a total score (0–10, α = 0.87) and four subscales scores, addressing physical (0–10, α = 0.66), psychological (0–10, α = 0.85), existential (0–10, α = 0.57), and social quality of life (0–10, α = 0.71). An additional item assesses individuals’ overall, subjective quality of life. Higher scores reflect higher quality of life. The questionnaire was translated into French by the Canadian team who developed the MQoL-r.

Psychological distress: Hospital Anxiety and Depression Scale (HADS)
The HADS consists of 14 items rated on a Likert scale yielding a total score (0–42; α = 0.73), a depression score (0–21; α = 0.73), and an anxiety score (0–21, α = 0.66) (Zigmond and Snaith, 1983). Higher scores reflect higher levels of distress. The scale was validated in French (Razavi et al., 1989).

**Statistical analyses**
We used descriptive statistics to examine participants’ sociodemographic and medical characteristics and their levels of growth, psychological distress, and quality of life. Based on the PTGI results, we further assessed the prevalence and most salient dimensions of growth. Pearson correlations were performed to explore associations between PTG (PTGI total score), quality of life, and psychological distress. Finally, we performed linear regression to examine which factor(s) could predict growth (PTGI total and subscale scores), controlling for age, sex, education level, civil status, and health status. Given the exploratory nature of this study, we used backward elimination procedures to identify the model with the best predictive value — as there is less risk of making type II errors than with the stepwise and forward methods. We also performed a Bonferroni correction (for multiple comparisons) to limit potential type I errors due to multiple comparisons — with a significance level set at $p = 0.01$ since we have five subscales.

We established a minimum threshold of 10–15 observations for each predictor (Bressoux, 2010). To manage missing data, we calculated quality of life and PTG scores using mean imputation, as long as there was no more than one missing item per subscale (Cohen et al., 2017). For the HADS, we calculated subscale means if at least half of the items had been answered (Bell et al., 2016). Data analysis was performed using SPSS for Windows version 24.

**Results**

**Participants**
The clinical team identified 164 patients as eligible for this study, 100 (61%) of whom were informed but did not participate, for the following reasons: unwilling to participate (26 patients), no longer a patient of the palliative care service (22), worsening psychological or cognitive problems (16), physical problems (15), emergence of other exclusion criteria (communication or not clinically stable) (11), deceased (7), and cannot be reached (3). Sixty-four patients (39%) agreed to participate, seven of whom did not provide any answer to the PTGI, and two of whom had more than one missing data per PTGI subscale. The 55 participants (34% of eligible patients) who completed the PTGI are included in this study. Their demographic and medical characteristics are shown in Table 2.

**Prevalence of PTG**
Twenty-four (44%) participants reported no to low growth (IC: 30.5–56.7%), 26 (47%) moderate growth (IC: 34.1–60.5%), and 5 (9%) high to very high growth (IC: 1.5–66.7%).

**Most salient areas of growth**
When standardizing mean scores to allow for meaningful comparison, participants scored highest in the areas “appreciation of life” (14.1/20; original $x = 10.6$ [0–15]) and “relating to others” (13.4/20; original $x = 23.4$ [0–35]), followed by “personal strength” (11.4/20; same as original), “new possibilities” (10/20; original $x = 12.5$ [0–25]), and “spiritual change” (8/20; original $x = 4$ [0–10]).

**Bivariate associations of PTG with psychological distress and quality of life**
Table 4 shows Person correlations between growth, psychological distress, and quality of life. We found significant negative correlations between PTG and psychological distress (total HADS score), and between PTG and depression (HADS depression score).
There was no significant correlation with quality of life (total and subscale scores of the MQoL-r) or with anxiety.

**Bivariate associations between positive and negative illness-related changes**

Pearson correlation between reported positive and negative changes on patients’ lives and/or personalities was negative but not significant ($r = -0.167$, $p = 0.228$).

**Multivariate associations of PTG with psychological distress and quality of life**

We performed regression analyses on the PTGI total score and each PTGI area of growth in relation to psychological distress.
(HADS depression score and anxiety score) and quality of life (MQoL-r total score). The final model explains 21.9% of total variance for the PTGI total score, 40.2% of total variance in the area “appreciation of life,” 23.3% in “personal strength,” 17.4% in “new possibilities,” and 13.7% in “relating to others.” No significant model was found for “spiritual change.” As shown in Table 5, depression (HADS depression score) is the only variable associated with the PTGI (total score and subscales). It is significantly and negatively associated with the PTGI total score and with the areas “relating to others,” “personal strength,” and “life appreciation.”

Discussion
To investigate whether PTG is an empirically relevant concept for palliative care patients, this study’s first aim was to assess PTG in terms of prevalence and areas of growth. We found that 44% of our participants experienced no growth or low growth, 47% moderate growth, and 9% high to very high growth. With 56% of palliative patients reporting moderate to very high PTG levels, our study reveals a prevalence level similar to that of cancer patients (46% to 73%), and higher than heart disease survivors (47%) (Bluvstein et al., 2013; Wu et al., 2019). Our results are particularly close to those of women with breast cancer (57–59%), adolescents and young adults with cancer (59%), and open heart surgery patients (57%) (Wu et al., 2019). While PTG prevalence rates should be compared with caution, as different studies might use different cutoffs, over half of palliative patients reported experiencing significant positive changes following the trauma of their illness. About 1 in 10 of our patients experienced high to very high growth, suggesting that PTG is a process worthy of further consideration and exploration in palliative care.

With an overall PTGI mean score of 61.5, our participants experienced levels of growth similar to those of cancer survivors 3 years after diagnosis (61) and hospice patients who experienced end of life dreams and visions (64); significantly higher than non-dreaming hospice patients (50), terminal cancer patients (52), women with advanced breast cancer (44), and heart disease survivor (ranging 41–58); and lower than men with advanced cancer (76) (Mystakidou et al., 2008, 2015; Morris et al., 2012; Rand et al., 2012; Bluvstein et al., 2013; Tang et al., 2015; Levy et al., 2020). While our participants’ mean score is still classified as low (just under the 63 cutoff), it is located at the higher end of growth levels reported by those with serious illness.

Areas where participants experience the greatest levels of growth are “appreciation of life” and “relating to others,” mirroring the areas of positive changes identified by palliative hospice patients, patients with advanced cancer, and cancer survivors (Moore et al., 2011; Morris et al., 2012; Levy et al., 2020). As shown by a grounded theory study with breast cancer patient, serious illness can lead people to feel more grateful for and appreciate “the small, intangible things in life” (Zhai et al., 2021). Indeed, appreciation, defined as acknowledging the value and meaning of something (event, person, behavior, or object) and feeling a positive emotional connection to it, is a core concept of gratitude (Adler and Fagley, 2005; Rusk et al., 2016), which is also strongly and positively linked with PTG, as shown in our previous publication (Althaus et al., 2018). Recognizing the fragility of life, some people also make a conscious decision to enjoy every moment they live; in the word of a participant: “No matter how long you live, what counts the most is how happy you are in this process” (Zhai et al., 2021). Our findings further underline the importance of interpersonal relationships at the end of life, which were found to improve quality of life and give meaning to the lives of palliative patients (Stiefel et al., 2008; Fegg et al., 2010; Giovannetti et al., 2016; Bernard et al., 2020).

The second aim of this study was to explore associations between PTG, psychological distress, and quality of life. Overall, our final model explained 21.9% of the PTG total score variance and between 13.7% and 40.2% of variance for single PTG areas. Our results indicate that PTG is linked with psychological distress and between PTG, psychological distress, and quality of life. Overall, our final model explained 21.9% of the PTG total score variance and between 13.7% and 40.2% of variance for single PTG areas. Our results indicate that PTG is linked with psychological distress and between PTG, psychological distress, and quality of life. Overall, our final model explained 21.9% of the PTG total score variance and between 13.7% and 40.2% of variance for single PTG areas.

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Table 5. Final models from linear regression for the PTGI (total score and subscales)

| Dependent variables | Independent variables | Standardized Coefficient β | T   | p       | CI (95%) |
|---------------------|-----------------------|---------------------------|-----|---------|---------|
| Total score         | (Constant)            |                           | 17.549 | 0.000 | 67.259 | 84.617 |
| Depression (HADS depression score) | −0.468 | −3.851 | 0.000 | −3.045 | −0.959 |
| Relating to others  | (Constant)            |                           | 16.000 | 0.000 | 24.189 | 30.704 |
| Depression (HADS depression score) | −0.371 | −2.905 | 0.005 | −0.958 | −0.175 |
| Personal strength   | (Constant)            |                           | 13.793 | 0.000 | 12.935 | 17.337 |
| Depression (HADS depression score) | −0.482 | −4.008 | 0.000 | −0.793 | −0.264 |
| New possibilities   | (Constant)            |                           | 10.369 | 0.000 | 11.928 | 17.653 |
| Depression (HADS depression score) | −0.314 | −2.483 | 0.016 | −0.749 | −0.080 |
| Life appreciation   | (Constant)            |                           | 16.843 | 0.000 | 12.502 | 15.886 |
| Depression (HADS depression score) | −0.413 | −3.669 | 0.001 | −0.496 | −0.145 |

CI, Confidence interval; HADS, Hospital Anxiety and Depression Scale.
The significance level is at p = 0.01 with Bonferroni correction.
overtime. When considering the ensemble hypothesis on human cognitive abilities (Kellogg et al., 2020), depressive disorders are associated with excessively pessimistic explanatory styles and persistent negative rumination. Thereby, people tend to focus on and blame themselves for negative past experiences, leading to difficulties in imagining a positive future. Based on our results, we could hypothesize that experiencing PTG processes — gaining a greater appreciation of life or developing better relationships, for instance — lessen such pessimistic, self-blaming outlook. Such interpretation finds support in longitudinal studies, which found that overtime, PTG is a predictor of lower levels of depression (Tanyi et al., 2020). As proposed in PTG theory, growth might be best understood as an initially challenging, difficult process of self-introspection and reconstruction, from which positive psychological effects may emerge in the long run.

That is not to say that growth replaces or roots out negative psychological processes. Indeed, the non-significance of the negative association between positive and negative changes reported by our participants supports one of the key postulates in PTG theory, namely that positive and negative psychological responses to trauma are likely to coexist, and that mental “health” and “illness” evolve on two linked but distinct continua (Westerhof and Keyes, 2010). This might further help to explain the lack of a clear correlation between PTG and anxiety, which is characterized by an excessive anticipation of danger, alongside anticipation of positive future events (Miloyan et al., 2014; Pomerantz and Rose, 2014). Faced with the heightened threat of advanced illness, people may thus simultaneously experience deep appreciation of the present moment and strong worrying about their future.

Our results further indicate that PTG is not associated with quality of life. This is aligned with findings from young adult cancer survivors and colorectal and hepatobiliary carcinoma cancer patients, but differ from results in breast cancer patients, for whom the two dimensions are positively associated (Casellas-Grau et al., 2017). One possible explanation for this lack of association is that at the end of life, other dimensions could “override” PTG processes in determining quality of life — such as relationships, a quality of life area where our participants scored particularly high. Overall, our findings underline the importance and uniqueness of the PTG concept in understanding the experience of those living with serious illness, capturing how they may give deeper meaning and gain greater appreciation of life in the aftermath of trauma — which is different from assessing one’s own, current life as good or satisfying through a questionnaire like the MQoL-r (Tedeschi et al., 2015).

This study has several limitations. Firstly, the PTGI has been criticized for occasionally eliciting responses that reflect “defensive” growth geared towards maintaining self-esteem and control, rather than “true” growth (Zoellner and Maercker, 2006; Calhoun and Tedeschi, 2013). Secondly, we cannot infer causal relationships based on a cross-sectional design, which is an important limitation when investigating a transformational process like PTG. Thirdly, our relatively small sample size resulted in low statistical power and limited generalizability. As such, we were not able to explore potential associations between growth and quality of life subscales — although it would have been particularly interesting to investigate potential links between the PTG area “relating to others” and social quality of life, both of which explore aspects of participants’ relationships, such as communication, support, and compassion. Fourthly, the application of our exclusion criteria, coupled with people’s refusal or inability to participate, resulted in a low participation rate — a frequent occurrence in palliative care studies. This may have induced a selection bias, with better-off patients more likely to participate than those experiencing higher levels of psychological or physical distress (White and Hardy, 2010). Finally, we did not collect data on posttraumatic stress disorder, which would have given us a more complete picture of the positive and negative responses to trauma in palliative patients. We also lack data on participants’ religious and spiritual beliefs, which would have provided context to the PTG spiritual subscale results, and information on what people experienced as trauma and when it occurred, which could have helped to make sense of results on growth intensity and on the nature of illness-related trauma.

To gain a better understanding of the dynamic nature of PTG, future research could adopt longitudinal designs to investigate the psychological trajectories of patients overtime, in terms of both distress and growth. In addition, in order to overcome the biases inherent to the use of self-report questionnaires, future research could explore growth through patients’ autobiographical life narratives (McAdams, 2001; Wengraf, 2001). This approach, which builds upon narratives of identity and personality development, presents an interesting new perspective for examining the cognitive and emotional processes and determinants of PTG.

Conclusion

Fifty-six percent of study participants reported moderate to very high PTG levels. We believe that this makes PTG a process worthy of further consideration and exploration in the context of palliative care. Moreover, this study uncovered a significant negative association between growth and depression. These results highlight the importance of considering PTG in the psychological care of palliative patients, which offers the possibility of “living a life at a deeper level of personal, interpersonal, and spiritual awareness” (Tedeschi et al., 2015). Interventions geared towards fostering growth, including narrative and expressive therapies (Calhoun and Tedeschi, 2013), may thus represent promising avenues to improve the experience of individuals in palliative care. To maximize the potential of such interventions, we must first gain a better understanding of the patterns and dynamics underlying PTG processes. A study utilizing a life narrative approach to this effect is currently in preparation.

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Conflict of interest. The authors declared none.

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